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Experiences of dementia: Parental young onset dementia and living alone

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This thesis is submitted in part fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

Coventry University, Faculty of Health and Life Sciences

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List of Abbreviations

BPS	British Psychological Society
CINAHL	Cumulative Index of Nursing and Allied Health Literature
IRAS	Integrated Research Application System
I1, I2, I3...etc	Informant 1, Informant 2, Informant 3...etc
LOD	Late Onset Dementia
P1, P2, P3...etc	Participant 1, Participant 2, Participant 3...etc
PRISMA	Preferred Reporting Items for Systematic Reviews
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
YOD	Young Onset Dementia

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- E Participant invitation emails for volunteers on the online database
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- I Consent form (person with dementia)
- J Consent form (informant)
- K Participant information sheet (person with dementia)
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- M Debrief sheet
- N Initial coding – example transcript excerpt

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Thank you to my wonderful family: my mum, who is always only one call away; my sister Evie, who encourages me to push for the stride; and my nan, who never, never fails to make me smile. Thanks also to JK, whose imagination has been a magical escape.

Finally, thank you to Nick, whose support throughout has been unwavering. You've put up with my thinking out loud, helped me to make a little lemonade and always been there to lean on. None of this would have been possible without you.

Declaration

This thesis has not been submitted for any other degree or to any other institution. The literature review was conducted under the supervision of Dr. Tom Patterson (Clinical Psychologist, Coventry University), who assisted in the development of a topic and read drafts of the chapter. Tony Colombo (Research Methods Tutor, Coventry University) also provided guidance on analysis. A colleague cross-rated the quality appraisal checks for reliability assessment.

The empirical paper was supervised by Dr. Tom Patterson (Clinical Psychologist, Coventry University), Dr. Anna Buckell (Clinical Psychologist, Worcestershire Dementia Assessment and Treatment Team) and Dr. Jane Muers (Clinical Psychologist, Rugby Dementia Support Group). All supervisors assisted in the development of the research idea and provided suggestions and feedback throughout the research process. Additionally, all supervisors read and commented on drafts of the empirical chapter. Another colleague was involved in cross-coding a transcript for reliability checks.

Apart from the collaborations stated above, all material presented in this thesis is my own work.

Summary

This thesis explores experiences of dementia from different perspectives. A diagnosis of dementia has a significant impact on the person themselves and the friends and family members who support them. How dementia is experienced will be influenced by contextual factors, such as age and living situation for the person with dementia, or relationship to the person with dementia for close friends or family members. Through exploration of these factors, this thesis aims to contribute to the literature on experiences of dementia and to inform future clinical and research practice.

The first chapter is a systematic literature review exploring experiences and needs of children who have a parent with young onset dementia. Findings from 16 studies were critically evaluated and synthesised using a meta-ethnographic approach. Three themes explained children's experience of their parent's deterioration and the psychological and practical impact that it has on them. Each theme is explored and recommendations regarding support for children of people with young onset dementia are considered.

The second chapter presents a grounded theory study into the phenomenon of living alone with dementia. Seven people living alone with dementia and seven friend and family 'informants' were interviewed, and a three-level data-grounded theoretical model was developed from the findings. The model is presented and unique concepts are discussed: experiences of aloneness and concerns about the future. The model is used to recommend avenues for informal and professional support to help people to live alone successfully with dementia.

The third chapter presents a reflective report on the author's experience of conducting research with people with dementia. It explores the assumptions, biases and beliefs about dementia that arose and were challenged at different stages during the research process. It also suggests how the learning resulting from reflection on this research can inform future clinical and research situations.

Chapter 1: Literature Review

**Experiences and needs of children who have a parent with
Young Onset Dementia: A meta-ethnographic review.**

*In preparation for submission to International Psychogeriatrics (see
Appendix A for author instructions)*

Overall chapter word count at submission (excluding abstract, tables,
figures and references): 7883

1.1. Abstract

Dementia that starts before the age of 65 is referred to as Young Onset Dementia (YOD). YOD presents unique psychological, social and practical challenges, not least of which is the impact on the person's children. The aim of the present review was to critically evaluate empirical evidence regarding the needs and experiences of children who have a parent with YOD. A systematic search of five databases was carried out and the resulting 16 studies were reviewed using a meta-ethnographic approach. Three main themes arose from the data: 'Dementia Impact', which describes how the child experiences the deterioration in their parent and changes to their relationships; 'Psychological Impact', comprising the child's private emotional experiences and the psychological consequences of changes in roles; and 'Practical Impact', detailing the ways in which children adapt their lives in response to parental YOD, and children's needs for support. These themes synthesise the existing literature and produce a line of argument explaining the experience of children whose parents have YOD. The findings have important implications for policy development and service provision. Research implications are also discussed.

(Word count: 180)

Key words: young onset dementia, children, needs, experiences, meta-ethnography

1.2. Introduction

1.2.1. Young Onset Dementia

Dementia is a progressive loss of cognitive function that can result from a variety of different diseases of the brain (World Health Organisation [WHO], 2012). It is often thought of as a disease of older age, but 5.2% of people diagnosed with dementia in the United Kingdom (UK) are aged under 65 (Prince et al., 2014). Dementia that starts before the age of 65 is referred to as “early onset dementia”, “working age dementia”, “presenile dementia”, or the preferred term “young onset dementia” (Alzheimer’s Society, 2015).

Young onset dementia (YOD) has a much wider range of underlying causes than late onset dementia (LOD), and 20-25% of YOD diagnoses are rarer forms of dementia (Alzheimer’s Society, 2015). It can present with a variety of behavioural and personality changes and a wide range of cognitive and neuropsychiatric difficulties, including visuospatial deficits and language impairments, which can lead to frequent misdiagnosis (Mendez, 2006). There is often a much longer time period between early symptoms and diagnosis in YOD compared to LOD, as both family members and clinicians may be less likely to consider dementia in younger adults (van Vliet et al., 2013). The younger a person is diagnosed with dementia, the more likely it is that there will be a genetic component to the disease; approximately 10% of YOD cases are thought to be hereditary (Alzheimer’s Society, 2015).

As well as clinical differences, YOD can present a range of different psychological, social and practical challenges than LOD due to the life stage at which people are affected. The person’s young age makes the diagnosis much less expected than for older people and disrupts the anticipated life cycle; receiving a diagnosis of dementia “out of time” can exacerbate the distress experienced by the person and their family (Greenwood & Smith, 2016). People with YOD may be excluded from relevant services because of their age, or may find that activities in services for dementia are inappropriate for them, having been contextually designed for older

cohorts (Alzheimer's Society, 2015). By definition, people with YOD are of working age, and therefore may be more likely to be the family's financial provider and have heavy financial commitments such as a mortgage. People with YOD typically describe a deep sense of loss at having to give up work due to dementia, and report a significant impact upon their identity as well as income (Rabanal, Chatwin, Walker, O'Sullivan & Williamson, 2018).

1.2.2. Impact of YOD on Caregivers

Importantly, people with YOD may be parents of relatively young children or may have dependent parents who are still alive, thus the impact on the family may be greater than that of LOD (Werner, Stein-Shvachman & Korczyn, 2009). Caregivers of people with YOD report higher levels of caregiver burden (Freyne et al., 1999) and greater perceived difficulty in coping with behavioural symptoms than caregivers of people with LOD despite similar clinical features (Arai, Matsumoto, Ikeda & Arai, 2007), and 66% of caregivers of people with YOD perceive their wellbeing as poor or very poor (Williams, Dearden & Cameron, 2001). Higher stress levels in this group of carers may result from their younger age, longer duration of caregiving and lack of formal and informal support (Arai et al., 2007).

Whilst caregivers of people with YOD are often spouses, their children may also be involved in caregiving. A "young carer" is defined as a young person under the age of 18 (or under 25 in some services; Cree, 2003) who helps to look after a relative who is unwell, disabled or misuses drugs or alcohol (Carer's Trust, 2015). A national survey of young carers in the UK found that 50% were caring for someone with a physical illness, 29% for someone with a mental illness, and the remainder for people with learning difficulties (17%) or sensory impairments (3%; Dearden & Becker, 2004). It is not clear how dementia was categorised in this survey.

Young carers are often significantly impacted by their caring role (Cree, 2003). Children whose parents have a serious physical illness (such as cancer) have been found to be at higher risk of experiencing anxiety, depression, somatic complaints

and social withdrawal (Barkmann, Romer, Watson & Schulte-Markwort, 2007). Similarly, children whose parents have a mental illness (including depression, psychosis and eating disorders) report worrying about their parent and receiving little information or support in relation to their parent's illness (Stallard, Norman, Huline-Dickens, Salter & Cribb, 2004).

Adult-children can also be affected by parental illness, whether or not they still reside with the parent. Adult-children of parents with mental illness reported feeling uncertain, struggling to connect with their ill parent and with peers and having to grow up quickly and take on responsibility (Foster, 2010). Compared to spousal caregivers, Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch & Lopez-Pousa (2010) found higher levels of caregiver burden in adult-children of people with dementia and higher levels of guilt in adult-children who did not live with the parent with dementia. Adult-children may have additional responsibilities, such as employment or being a parent themselves, which can add to the impact of supporting a parent with dementia (Wang, Shyu, Chen & Yang, 2011).

Although the impact of parental illness is beginning to be better understood, services often do not offer specific support for children of patients under their care, particularly within mental health services (Somers, 2007). Stallard et al. (2004) identified a number of service barriers to recognising the psychological needs of children living with a parent with mental illness, including the client-focussed nature of services and time pressures which may limit the extent to which clinicians are able to explore the child's needs. Internationally, the involvement of caregivers in dementia services is a key priority (WHO, 2012). However, the extent to which caregiver support groups and training courses are suitable for children, particularly those aged under 18, is unclear.

1.2.3. Rationale

Although there have been several reviews of research examining caregiving in YOD, most of these have explored the experiences of family caregivers in general, with

spousal caregivers forming the vast majority of participants (Baptista et al., 2016; Millenaar et al., 2016; Spreadbury & Kipps, 2019; Svanberg, Spector & Stott, 2011; van Vliet, de Vugt, Bakker, Koopmans & Verhey, 2010). One review (Cabote, Bramble & McCann, 2015) considered the experiences of children and spouses separately but drew upon findings from only two studies that directly examined the child's experiences.

To date, there has been only one attempt to review the literature on children's experiences of parental YOD. Gelman & Greer (2011) conducted a narrative review of the literature on child caregivers (more generally) and found that, at the time, there were no published studies specifically exploring the experience of children of parents with YOD. They reviewed three studies indirectly addressing the topic, before presenting a case-study of a family intervention for YOD. Limitations of their review included not adopting a systematic approach to searching for studies and not presenting a synthesis of findings. Since this review, there has been increasing research interest in the experiences of children of people with YOD, yet there has been no review of this developing body of literature. A systematic literature review would therefore be beneficial at this time, in order to synthesise and critically appraise the existing evidence regarding the experiences and needs of children of parents with YOD, which in turn could helpfully inform future directions for service provision and further research in this area.

The present review will therefore critically evaluate empirical evidence regarding the experiences and needs of children who have a parent with YOD. Specifically, it will address the following questions:

- What is the experience of children of people with YOD?
- What is the impact of YOD on children's psychosocial wellbeing?
- What support needs do children of people with YOD have?

1.3. Methods

1.3.1. Systematic Literature Search

A systematic search for relevant studies was carried out using databases pertaining to the disciplines of psychology, medicine, gerontology and nursing. Five online databases were searched: PsychINFO, Embase, PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Web of Science. Reference lists of selected papers were searched manually for additional relevant papers.

The following search terms were used for the concept of young onset dementia: young onset, early onset, working age or presenile dementia; frontotemporal dementia or degeneration; dementia under 65; early onset or young onset Alzheimer's disease. For children, the terms child, children, son, daughter, young carer, parent, mother and father were used. These terms were consistent with those used in three previous reviews of family caregiver experiences of young onset dementia (Cabote et al., 2015; Svanberg et al., 2010; van Vliet et al., 2010), but extended with additional terms relating to children and parents. Frontotemporal dementia (or degeneration) was included as a specific search term, as this type of dementia is most commonly diagnosed in people under the age of 65 (Alzheimer's Society, 2016), and is often used as a standalone term in research. Relevant papers might therefore have been missed without this additional search term. Titles, abstracts, full texts and key words were searched.

The search terms were combined as follows: (((dementia OR Alzheimer*) N3 ("early onset" OR "young* onset" OR "working age" OR "under 65" OR "presenile"))) OR ((front*) N3 (dementia OR degeneration))) AND ((child* OR son OR sons* OR daughter* OR "young carer") OR (mother* OR father* OR parent*)).

1.3.2. Inclusion and Exclusion Criteria

The titles and abstracts of the generated references were screened for eligibility. Where there was any doubt, full texts were accessed and assessed for eligibility.

Studies were included if they were written in English, published in peer-reviewed journals and discussed empirical studies. No date limit was put on the search. The following inclusion and exclusion criteria were applied (see Table 1.1):

Table 1.1.

Inclusion and exclusion criteria for systematic search.

	Inclusion	Exclusion
Research design	Qualitative, quantitative or mixed methods studies	Review papers, opinion papers
Quality	Peer-reviewed empirical studies	Unpublished or grey literature, non-peer-reviewed sources
Concepts	Experience or impact of having a parent with young onset dementia	Epidemiology or genetics, interventions or treatments
Sample	Children of people who were diagnosed with dementia under the age of 65. No age limit for child.	Children of people with late-onset dementia, other family caregivers, patients with dementia, children of people with other physical or mental health conditions

Empirical studies which focussed on the experience of children whose parents have YOD were included regardless of methodology. Studies where the primary focus was on epidemiology, genetics or interventions for YOD or caregivers were excluded.

The sample of interest was children of people with YOD, therefore studies where the person with dementia was diagnosed at age 65 or above were excluded. No age limit was set for the children, in order to enable the experiences of adult-children to be captured as well as younger children. Although there may be differences between older and younger children, it is important to understand the commonalities in experience and needs of this group. Additionally, this area of

research interest has only begun to grow in the past 10 years and including children of all ages allows for a comprehensive review of the existing literature.

Studies primarily exploring the experiences of the person with dementia or other family caregivers (for example spouses), were excluded. Additionally, as the focus of the present review was on the unique experience of parental YOD, studies of children of parents with other mental or physical health conditions were excluded.

1.3.3. Classification of Studies

Sixteen studies were included in the final review. See Figure 1.1. (PRISMA Flow Diagram).

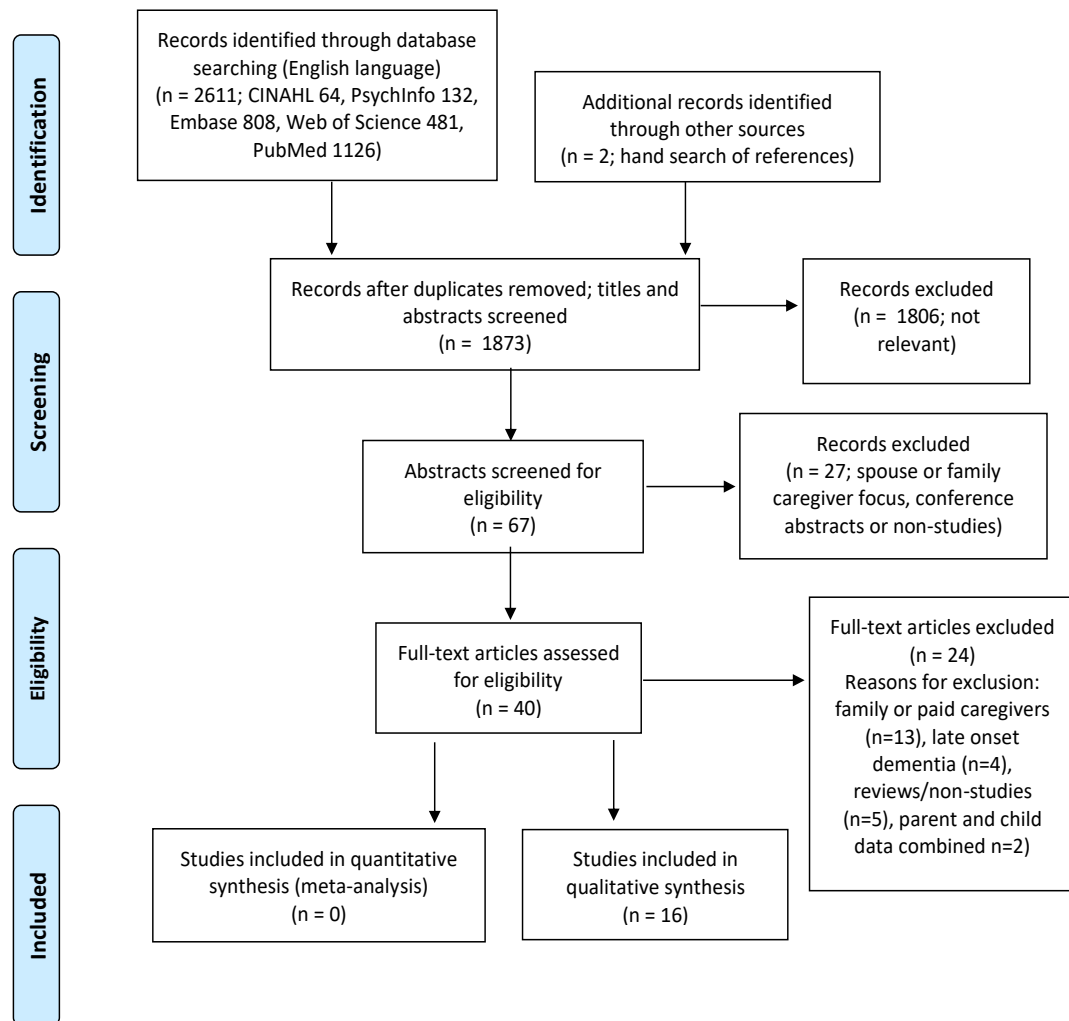


Figure 1.1. PRISMA flow diagram

1.3.4. Quality Assessment

Quality assessment is a key component of quantitative literature reviews, as it prevents the inclusion of poor-quality research trials where there may bias (Atkins et al., 2008). However, in the field of qualitative literature, there is very little consensus as to what criteria constitute high-quality research, and despite the large number of quality assessment tools available, there is no established protocol as to which is the most suitable for particular types of study (Ring, Ritchie, Mandava & Jepson, 2011). Difficulties include the diversity of qualitative research designs preventing direct comparison across studies (Mays, Pope & Popay, 2005), and different journal requirements making the level of methodological and ethical

detail variable. It is agreed, however, that some form of quality appraisal is important to the systematic review process, in order to enable confidence in the resulting conclusions (Dixon-Woods, Shaw, Agarwal & Smith, 2004).

For the present review, the quality appraisal framework suggested by Caldwell, Henshaw & Taylor (2011) was used (see Appendix B). This framework provides a set of prompt questions that comprehensively assess all aspects of both qualitative and quantitative research. It considers different methodological approaches and allows for comparison across the full range.

Each element of the framework was rated as 0 (criterion not met), 1 (criterion partially met) or 2 (criterion fully met) for each paper. The sum of these ratings provided a total score for each paper out of a possible 36. In order to assess inter-rater reliability, each paper was then cross-rated by a second assessor and a Kappa statistic was calculated from the two sets of ratings. The resulting inter-rater reliability Kappa score was $K=0.85$ ($p>.001$), indicating a good level of agreement.

A cut-off at the mid-point 18 was used as a guide to retention of studies, though no study fell below this point. The quality appraisal process was additionally used as a tool to deepen the critical understanding of the included studies.

1.3.5. Characteristics of Studies

See Table 1.2. for a summary of the key characteristics of the 16 studies included in the present review.

Table 1.2.

Summary characteristics of the studies

Authors	Year	Title	Location	Aims	Participants	Methodology	Main Findings
Allen, Oyeboode & Allen	2009	Having a father with young onset dementia: The impact on wellbeing of young people	UK	Explore impact of parental YOD on children's wellbeing	12 young people aged 13-24 years, 7 female, 5 male	Qualitative. Interviews; grounded theory	5 main categories: <i>Damage of Dementia, Reconfiguration of Relationships, Strain, Caring and Coping</i> - overarching theme of <i>One Day at a Time</i>
Aslett, Huws, Woods & Kelly-Rhind	2017	'This is killing me inside': The impact of having a parent with young-onset dementia	UK	Explore personal meaning attached to having a parent with YOD, impact on self and relationships	5 participants aged 23-36 years, 2 male, 3 female	Qualitative. Interviews; IPA	5 super-ordinate themes: <i>"Like I know them but I don't know who they are", "You just look up to them for all your life and then now they're looking to you for help", "I feel like she can get things off her chest", "You're never going to understand until you are in my position", "Hang on a minute, this could happen to...to me"</i>
Barca, Thorsen, Engedal, Haugen & Johannessen	2014	Nobody asked me how I felt: experiences of adult children of persons with young-onset dementia	Norway	Explore how adult children experience parental YOD and what needs they have	14 participants aged 20-37 years, 12 female, 2 male	Qualitative. Interviews; modified grounded theory	2 main themes: <i>Experiences in Social Relationships</i> (Changes in Roles and Relationships, Individuals with Different Family Contexts and Experiences), and <i>Experiences and Needs Related to Services</i> (Being Seen as a Person with Individual Needs, Targeted Groups, Need for Information)

Hall & Sikes	2016	How do young people "do" family where there is a diagnosis of dementia?	UK	Explore perceptions and experiences of parental YOD and impact on family practice and display	22 participants aged 6-31 years, 18 female, 4 male	Qualitative. 2-3 interviews; thematic analysis	3 main themes: <i>Disruption to Existing Practices, Continuities, and Reconceptualisation of Relationships</i>
Hall & Sikes	2017	"It would be easier if she'd died": Young people with parents with dementia articulating inadmissible stories	UK	Explore inadmissible stories in relation to parental YOD	22 participants aged 6-31 years, 18 female, 4 male	Qualitative. 2-3 interviews; thematic analysis	3 main themes: <i>The Process of Narrating Dementia, "Taboo" Subjects</i> (I don't like my ill parent, Death or other illnesses as preferable, Difficult dementia behaviours), and <i>Portrayals of Dementia by People Without Dementia</i>
Hall & Sikes	2018	From "What the Hell Is Going on?" to the "Mushy Middle Ground" to "Getting Used to a New Normal": Young People's Biographical Narratives Around Navigating Parental Dementia	UK	Explore perceptions and experiences of parental YOD	22 participants aged 7-31 years, 18 female, 4 male	Qualitative. 2-3 interviews; thematic analysis	3 overarching themes: <i>Something is Amiss, Navigating the Pathway, and The Unpredictability of Dementia</i>

Hutchinson, Roberts, Daly, Bulsara & Kurrle	2016a	Empowerment of young people who have a parent living with dementia: a social model perspective	Australia	Explore lived experiences of parental YOD from the perspective of a social model of disability and explore influencing factors that enable children to be included	12 participants aged 10-33 years, 1 male, 11 female	Qualitative. Interviews; thematic analysis	3 main themes: <i>Invisibility</i> (Isolation, Neglect, Perceptions of Marginalisation), <i>Connectivity</i> (Family and Friends, Health and Service Providers, Education) and <i>Being Empowered</i> (Self-Efficacy, Collaboration)
Hutchinson, Roberts, Kurrle & Daly	2016b	The emotional well-being of young people having a parent with younger onset dementia	Australia	Explore lived experiences of parental YOD from the perspective of a social model of disability and explore impact of society on the emotional wellbeing of children of YOD	12 participants aged 10-33 years, 1 male, 11 female	Qualitative. Interviews; thematic analysis	4 main themes: <i>Emotional Toll of Caring, Keeping the Family Together, Grief and Loss, and Psychological Distress</i>
Johannessen, Engedal & Thorsen	2015	Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors	Norway	Investigate and interpret metaphorical expressions of experiences of parental YOD	14 participants aged 18-30, 9 female, 5 male	Qualitative. Interviews; phenomenological hermeneutic approach	4 core metaphors: <i>"My parent is sliding away"</i> , <i>"Emotional chaos"</i> , <i>"Becoming a parent to my parent"</i> and <i>"A battle"</i>

Johannessen, Engedal & Thorsen	2016	Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: a qualitative follow-up study	Norway	Explore the influence of parental YOD on adolescent development, coping strategies and recent changes to situation	14 participants aged 18-30 years, 9 female, 5 male	Qualitative. Follow-up interviews; modified grounded theory	Main category "Detachment" (Moving Apart, Greater Personal Distance, Calmer Emotional Reactions)
Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey & de Vugt	2014	The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study	Netherlands	Explore experiences and needs of children living with parents with YOD	14 participants aged 15-27 years, 8 female, 6 male	Qualitative. Interviews; inductive content analysis	3 main themes: <i>Impact of Dementia on Daily Life</i> (Changing Relationships, Managing Responsibilities versus Maintaining Own Life, Concerns About Future Perspectives), <i>Coping with the Disease</i> (Process of Acceptance, Avoidance, Relief of the Situation, Dealing with Changes), and <i>Need for Care and Support</i> (Timing of Care, Understanding of Dementia, Value of Communication and Social Support, Desire for Practical Guidance)
Nichols, Fam, Cook, Pearce, Elliot, Baago, Rockwood & Chow	2013	When Dementia is in the House: Needs Assessment Survey for Young Caregivers	USA and Canada	Explore experiences of parental frontotemporal dementia and children's needs at different points in illness	14 participants aged 11-18 years, 10 female, 4 male (including 2 grandchildren living with person with dementia)	Qualitative. Focus group; thematic analysis	7 themes: <i>Emotional Impact of Living with a Parent with FTD</i> , <i>Caregiving</i> , <i>Coping</i> , <i>Diagnosis</i> , <i>Relationships</i> , <i>Support</i> , and <i>Symptoms</i>

Sikes & Hall	2017	Every time I see him he's the worst he's ever been and the best he'll ever be': grief and sadness in children and young people who have a parent with dementia	UK	Explore dementia grief in parental YOD	22 participants aged 7-31 years, 18 female, 4 male	Qualitative. 2-3 interviews; thematic analysis	6 themes: <i>Diagnosis, Ongoing Loss, Life on Hold, Missing Landmark Events, Envy, and Coping or Not</i>
Sikes & Hall	2018a	It was then that I thought 'whaat? This is not my Dad: The implications of the 'still the same person' narrative for children and young people who have a parent with dementia	UK	Explore implications of "still the same person" narrative for parental YOD	19 participants aged 8-31 years, 16 female, 3 male	Qualitative. 2-3 interviews; thematic analysis	7 themes: <i>"They Had to Hollywood it", My Parent is a Different Person, My Parent Doesn't Know Me, My Parent is Not Very Nice, My Parent is Aggressive, My Parent is Suspicious, and My Parent Can't Talk to Me</i>
Sikes & Hall	2018b	The impact of parental young onset dementia on children and young people's educational careers	UK	Explore impact of parental YOD on education	24 participants aged 6-31 years (gender not specified)	Qualitative. 2-3 interviews; thematic analysis	5 themes: <i>Locating Parental Dementia with Reference to Educational Milestones, Dementia-Specific Challenges, Education as an Escape/Coping Mechanism, Dementia and Educational Choices, and Educational Institutions' Responses</i>

Svanberg, Stott & Spector	2010	'Just Helping': Children living with a parent with young onset dementia	UK	Explore experiences of children of YOD and impact of parental diagnosis	12 participants aged 11-18 years, 6 male, 6 female	Mixed methods. Interviews; grounded theory. 3 questionnaires; descriptive statistics	4 main categories: <i>Discovering Dementia</i> ("Something had changed" versus Growing Up with Dementia, "A right to know", "Working on it"), <i>Developing a New Relationship</i> ("I don't think he knew", "They're not themselves", "Like a child", Missing Out, The Grieving Process, "Trying to remember"), <i>Learning to Live with It</i> ("Just helping", "Getting on with it", "Making sacrifices", "Growing up", "Detaching myself", "Looking on the bright side", "Becoming a better person"), <i>Going Through it Together</i> (Working as a Team, Choosing to Share, "Taking the pressure off"). Quantitative: 4 above cut-off for depression or mood disorders, 7 above cut-off for high burden, mean resilience level 'moderate'.
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All studies had similar aims; to explore the impact, meanings, perceptions, experiences and/or needs of children related to their parent's YOD. Fifteen of the studies took a qualitative approach; 14 gathered data through interviews and one through a focus group (Nichols et al., 2013). One study used a mixed-methods approach (Svanberg, Stott & Spector, 2010), though the focus was on qualitative analysis of the interviews, with three questionnaires used to provide supporting data.

Participants in all studies were children of people with YOD, with the ages of participants ranging from 6 to 37 years across the studies. Two studies included only participants aged 11-18 (Nichols et al., 2013; Svanberg et al., 2010), and four included only adult-children aged over 18 (Aslett, Huws, Woods & Kelly-Rind, 2017; Barca, Thorsen, Engedal, Haugen & Johannessen, 2014; Johannessen, Engedal & Thorsen, 2015; Johannessen, Engedal & Thorsen, 2016). The remaining studies included participants across the full age range. Nine of the studies took place in the UK, three in Norway, two in Australia, one in the Netherlands and one in the USA.

In terms of quality assessment, all papers scored above the half-way mark of 18 out of 36, with a range of between 21-35. Lower scores were often due to insufficient detail on methodological aspects. Many of the papers did not explore ethical issues, though this may have been due to journal restrictions.

Notably, six of the 16 studies arose from the same interview dataset (Hall & Sikes, 2016, 2017, 2018; Sikes & Hall, 2017, 2018a, 2018b), while two further studies were also based on single dataset (Hutchinson, Roberts, Daly, Bulsara & Kurrle, 2016a; Hutchinson, Roberts, Kurrle & Daly, 2016b). One study (Johannessen et al., 2016) was a follow-up of the participants from another study (Johannessen et al., 2015). Therefore, 10 of the 16 papers resulted from interviews with three groups of young people, and caution must be taken in evaluating the evidence so as not to bias findings towards these experiences.

1.3.6. Analytic Review Strategy

The 16 papers determined from the systematic search were analysed using a meta-ethnographic approach, which was first described by Noblit and Hare (1988). The aim of a meta-ethnography is to bring together findings and interpretations from individual studies to form a new “third-order” level of understanding (Ring et al., 2011).

Three methods of synthesis are used in meta-ethnography: reciprocal translational analysis involves “translating” common or overlapping concepts between studies to form overarching themes, refutational synthesis explores and explains any contradictions between study findings, and line of argument synthesis builds a new picture of the whole from its parts (Barnett-Page & Thomas, 2009). An evaluation of meta-ethnography using qualitative research in healthcare found that it can produce new insights and research directions (Campbell et al., 2012).

Limitations of a meta-ethnographic approach include the use of the original authors’ interpretations of their data as a unit of analysis, meaning that without caution the conclusions could become far removed from the original data. Additionally, syntheses that include a large number of studies (over 40) can make it difficult for the researcher to maintain sufficient familiarity with the studies for their interpretations to remain grounded in the data (Toye, Seers, Allcock, Briggs, Carr & Barker, 2014). Care was therefore taken in the present review to evidence themes with original quotes, keeping the findings as grounded in the data as possible. Only 16 papers were found to meet the inclusion criteria, therefore allowing for sufficient familiarity with the studies.

The present analysis followed the process for meta-ethnography originally proposed by Noblit & Hare (1988), as described by Campbell et al. (2012; see Appendix C).

1.4. Results

The present review aimed to explore and synthesise evidence regarding the experience of children of people with YOD, their support needs and the impact of YOD on their psychosocial wellbeing. Table 1.3 details the main themes and subthemes that were developed from the meta-ethnographic analysis.

Table 1.3.

Main themes and subthemes.

Main theme	Subthemes
Dementia Impact	<i>Changes in Parent</i> <i>Changes in Relationships</i>
Psychological Impact	<i>Personal</i> <i>Interpersonal</i>
Practical Impact	<i>Adapting</i> <i>Needs for support</i>

1.4.1. Dementia Impact

The first theme, 'Dementia Impact' describes how the child experiences the deterioration of their parent as a result of YOD. Inevitably, their parent changes as the dementia progresses, and the child witnesses and has to make sense of these changes for themselves. Relationships also change as a result of dementia, most notably the child's relationship with the parent who has dementia, but also with other people around them as the changes in their parent create conflict or alienate the child from others who do not understand their experiences.

This theme includes two subthemes: *Changes in Parent* and *Changes in Relationships*.

1.4.1.1. *Changes in Parent*

Children observed a number of changes to their parent's functioning and behaviour as a result of young onset dementia. They spoke about their parent losing abilities and a deterioration or regression in the parent's behaviour, which some described as their parent becoming *"like a child"* (Aslett et al., 2017; Johannessen et al., 2015; Svanberg et al., 2010). Many studies talked of parental behaviours that the child found difficult to manage and experience; this was most often aggression, but also included sexual behaviours, communication difficulties, incontinence, hallucinations and falls. In particular, participants struggled with the constant process of change in their parent: *"Every time I see him he's the worst he's ever been and the best he'll ever be."* (Sikes & Hall, 2017, p.330).

As well as changes in behaviour and functioning, many children talked about their parent changing as a person: *"It felt as if someone had taken him out of his body and then put him into another, and he still looked the same."* (Johannessen et al., 2015, p.249). Some participants felt that their parent would hate the person they have become, and others said that they themselves now dislike their parent: *"...it makes someone who was a lovely character really easy to dislike and you have to really fight not to hate your own parent. And sometimes you fail in that."* (Sikes & Hall, 2018a, p.191). They compared their parent's dementia to other illnesses in which the parent is unwell but remains the person they know: *"My friend's mum recently died of MS [...] and that was gradual and deteriorating but she was still her mum right to the end."* (Hall & Sikes, 2017, p.1208).

The diagnosis of YOD helped some children to make sense of the changes in their parent and helped them to explain their parent's behaviour to others. For others, however, the diagnosis meant that there was no hope for recovery or improvement in their parent, unlike with other illnesses. Additionally, the diagnosis brought

about uncertainty regarding the progression of the illness and the amount of time the child had left with their parent: *"...I have no idea [...] if it will be a gradual turn or just be a sudden [sic], I have no idea at all."* (Hall & Sikes, 2017, p.1207).

1.4.1.2. *Changes in Relationships*

The changes children observed in their parent invariably led to a different type of parent-child relationship. Many children spoke about taking on additional responsibilities and providing some form of care for their parent, whether performing household tasks, supervising their parent or providing more intimate personal care. However, some children spoke about rejecting the label of "young carer", feeling that they were *"just helping"* (Svanberg et al., 2010, p.743). Many children described the change in relationship with their parent in terms of a reversal of the parent-child roles, or *"becoming a parent to my parent"* (Johannessen et al., 2015, p.250). Some adult-child participants reflected on the inability of their parent to be a grandparent and support them with their own children (Aslett et al., 2017). Conversely, one study reported an experience of the parent remaining a parental figure but losing their orientation to the present and consequently treating a teenager like a toddler (Hall & Sikes, 2016), though this paper scored lowest in quality appraisal and the findings may benefit from a replication study.

Other relationships were also affected by parental YOD and were often characterised by emotional distancing. Participants spoke about friendships becoming more superficial and extended family withdrawing as their parent's skills deteriorated and they felt unable to share their experiences with others: *"I'll sort of like distance myself, but I will never say like 'This is killing me inside'. And it is, but I...I don't talk about it to my friends because I just feel like that's something that people don't need to know."* (Aslett et al., 2017, p.12). Conflict between family members was also mentioned, as disagreements arose between children and their siblings or well-parents regarding the care of their parent with YOD. Some studies also reported on experiences of discrimination from the wider public (Hutchinson

et al., 2016a; Hutchinson et al., 2016b), although these were from the same dataset and may not replicate in other groups of children.

However, relationship change was not all negative, and some children spoke about friends and partners who provided emotional support, and the supportive influence of siblings who were experiencing the same situation: “...*thank god I have my sister because we can talk about it together.*” (Hutchinson et al., 2016a, p.661). Some participants talked about feeling closer to their well-parent as a result of sharing care tasks and providing mutual support, and some talked about improvements in a previously strained relationship with the parent with YOD.

1.4.2. Psychological Impact

As the child tries to make sense of and adjust to the changes in their parent with dementia and in their own relationships, they experience a range of overwhelming emotions. Grief forms a key part of the ‘Psychological Impact’ of parental YOD on children as they process the gradual and continual loss of their parent. Feelings towards the parent with dementia, the well-parent and the caring role itself also arise in response to the changes that YOD brings about.

This second theme is composed of two subthemes: *Personal*, which incorporates the child’s personal and private emotional experiences and *Interpersonal*, referring to psychological and emotional consequences of the new roles and relationships that result from their parent’s dementia.

1.4.2.1. *Personal*

Many participants reported feeling stressed by the changes in their parent and the demands of their caring role. Questionnaire-based data indicated high levels of caregiver burden in more than half of participants (Svanberg et al., 2010), though there were only 12 participants in this study which limits the generalisability of this finding. Several studies reported participants feeling overwhelmed, with some children indicating that the stress of having a parent with dementia at a critical

point in their own development had become such that they felt they could no longer cope and in some cases, wanted to die: *"I was self-harming, I was going to take my own life as well."* (Allen, Oyebode & Allen, 2009, p.471). Some children also talked about worry for themselves in the future in relation to the possible hereditary risk of YOD.

In addition to the stress of caring for a parent with YOD, children reported feeling angry and upset at the changes in their parent. Several studies reported participants experiencing psychological distress or *"emotional chaos"* (Johannessen et al., 2015, p.249), and some participants had sought help from mental health services. One participant reported feeling *"almost as if I was sort of failing a little bit"* (Sikes & Hall, 2018b, p.603) by asking for help. Svanberg et al. (2010) found that four of their 12 participants scored above the cut-off indicating depression or other mood disorders on a questionnaire measure, though again this small sample size necessitates caution in interpretation. Some participants reported feeling hurt and upset at the changes in their relationship with their parent, while others felt embarrassed or ashamed by their parent's behaviour: *"Strangers...like stare at you when he's not like acting quite normal. I haven't had any umm friends round while he's been like he is like [sic] to see him"* (Allen et al., 2009, p.469). One study, however, reported participants experiencing *"positive emotions arising from the situation"* (Nichols et al., 2013, p.23), though the authors did not provide participant quotes to evidence this so it is unclear to what emotions this might refer.

Grief, in some form, was mentioned as an element of children's experiences across all of the papers. In particular, children spoke of feeling that they were losing their parent and going through a process of constant grieving with each new change in them: *"...you start grieving even though they're standing right in front of you."* (Sikes & Hall, 2017, p.330). Some talked about the loss of shared experiences with their parent, such as the parent teaching them to drive or remembering their birthday, and others simply stated, *"You miss them being a parent."* (Millenaar et al., 2014, p.2004). Elements of grief were reported at different stages of the

parent's dementia: shock and denial at the initial diagnosis, relief and sorrow when the parent moved to a care home, gradual loss of the parental relationship throughout the dementia process, and the anticipatory loss of a shared future with the parent. Some papers spoke explicitly about death and participants' anticipatory grieving, with one participant reporting that they felt they were *"...waiting [...] to be told that he's died because you know it's coming...you just don't know how long you've got to wait."* (Sikes & Hall, 2017, p.330).

1.4.2.2. *Interpersonal*

The parent's changing abilities caused many participants to worry about their parent's safety and about the future, in terms of further deterioration in their parent and the possibility of needing a care home. Additionally, several studies reported children's concerns for their well-parent and the strain that the caring role had put on them. Many children spoke about hiding their own feelings in order to protect both parents and to avoid placing additional strain on the well-parent: *"There was lots of different things that I didn't, I didn't really want to burden [mum] with, that I'd bottle up."* (Svanberg et al., 2010, p.744).

Guilt formed another part of many children's experiences of their changed relationship to their parent with YOD. Some reported feeling guilty at continuing their own lives whilst their parent was living in a care home. Others reported guilt at their responses to the parent's behaviour, such as getting frustrated with them: *"...sometimes I do feel quite guilty because you...sometimes you snap, or you say 'Come on, let's get going', and it's pushing my Mum..."* (Aslett et al., 2017, p.10). Additionally, some reported feeling guilty about how they had thought badly of their parent before they learned that the changes in them were due to YOD.

Despite the challenges, participants in some studies reported positive aspects of caregiving or a positive psychological impact. For example, some children reported taking pride in their caring role and finding it rewarding: *"...you'd have to prompt her to get up and change her and dress her, put her socks on...it was a pleasure to*

be able to do that for her.” (Hutchinson et al., 2016b, p.615). Others spoke about how caring had made them a *“better person”* (Svanberg et al., 2010, p.744) and given them a level of maturity and confidence that they felt they would not otherwise have had. Additionally, a moderate to high mean resilience score was found in questionnaire data from one study, suggesting that those participants were coping relatively well with their situation (Svanberg et al., 2010). However, resilience was only explored in one study and this finding would benefit from a replication study with a larger sample.

1.4.3. Practical Impact

As well as the ‘Psychological Impact’ of parental YOD on children, the changes in their parent and the resulting caring role lead to a number of practical challenges, both in day-to-day life and in children’s life goals and plans. Some of these practical difficulties are unavoidable consequences of living with and supporting a parent with YOD, and others are decisions that the child makes themselves in order to manage their feelings about parental YOD. Children of people with YOD have unique needs for support and are under-recognised by services, as both the caring role and the dementia occur at a life stage where such changes would not usually be expected.

This final theme contains two subthemes: *Adapting*, covering ways in which children have to adapt their lives because of parental YOD, and *Needs for Support* which describes the types of support that children feel they need.

1.4.3.1. *Adapting*

Unsurprisingly, children reported that parental YOD had an impact on their day-to-day lives, aside from the caring tasks themselves. Several studies reported that children experienced disrupted sleep due to their parent’s behaviour during the night or due to worrying about their parent. Some children reported struggling to concentrate or missing a lot of school, with consequences for their educational achievement. Some of the adult-children reported difficulties balancing caring for

their parent with other responsibilities such as university work or their own children: *"...it's more juggling the time with him [baby] and Mum; you can guarantee accidents always happen at the same time [laughs]."* (Aslett et al., 2017, p.10). One study reported on the neglect that some children experience when the parent with YOD is unable to work or to care for them, for example financial struggles, inadequate nutrition and poor hygiene (Hutchinson et al., 2016b).

Feelings of guilt and grief led children to make changes to the plans and ideas they had for themselves. Several studies described children feeling that they had put their life *"on hold"* (Aslett et al., 2017; Sikes & Hall, 2017) or having to change their plans to spend more time with their parent or to fulfil their caring role. This included delaying moving out of the family home, delaying plans to have their own children and making decisions about further education and work that enabled them to stay closer to their parent or provide for the family: *"Since I was 15, when I knew that dad wasn't going to be bringing in any money for mum, it kind of put me more towards work than university and college."* (Allen et al., 2009, p.467). Some children felt that parental YOD had a different impact dependent on the child's age and gender, for example younger siblings missing out more on their parent's involvement in developmental milestones such as weddings and having children (Hall & Sikes, 2017), and different care roles being apportioned based on gender (Barca et al., 2014).

Children employed a number of coping mechanisms to reduce and manage the psychological impact of their parent's deterioration. Avoidant strategies included explaining away changes in their parent, distracting themselves with schoolwork or other activities, and moving out of the family home or getting on with their own lives: *"You try to continue with your life as normal as possible without things influencing you."* (Millenaar et al., 2014, p.2005). Additionally, children found ways of re-appraising their situation to make it more manageable, such as normalising caregiving, accepting uncertainty and the new version of their parent, and *"living in the moment"* (Aslett et al., 2017, p.14) or taking things *"one day at a time"* (Allen et al., 2009, p.472). Many children also talked about separating the person from

dementia, which allowed them to channel difficult feelings towards the diagnosis rather than the parent. A follow-up study found that most children experienced an improvement in their own wellbeing and relationship with their parent after gaining physical or cognitive distance from the situation (Johannessen et al., 2016).

1.4.3.2. Needs for Support

Almost all of the studies spoke about other people not understanding the child's unique experience of having a parent with YOD. Some participants reflected that other people didn't understand that someone of their parent's age could have dementia. One study reported the participant's view that other people expected her to be *"grateful that your Mum is still here and she's not dead"* (Hall & Sikes, 2017, p.1207), which reflected their lack of understanding at the experience of losing a parent while they are still alive. Many children felt they would benefit from meeting other young people whose parents have YOD, and those who had already done so reported experiencing a sense of understanding that came from the shared experience: *"Now I know that there is someone in the same situation as me living close by. It was wonderful to 'empty' myself and be understood."* (Johannessen et al., 2016, p.8).

Children talked about their difficulties in accessing appropriate support and services, both for their parent and for themselves. Some children spoke about difficulty accessing services in general, in terms of having to *"battle"* for support (Johannessen et al., 2015, p.251), or finding that services were aimed at older adults and weren't appropriate for their younger parent with dementia. Some participants described feeling *"powerless"* with services because of their age (Svanberg et al., 2010, p.744), and about not being recognised as an individual with their own needs separate to their well-parent and parent with dementia. Some felt that support should be more readily available: *"It [support] should be offered, because I would never have asked for it by myself."* (Barca et al., 2014, p.1940). Most of those who had received support from professionals had found it helpful, particularly when they received help in caring for the parent with YOD, and when

the professional was familiar to the family. However, some reported that professionals and services were unsupportive or unhelpful, because they were unfamiliar to the child or didn't provide guidance on how to respond (Nichols et al., 2013). Millenaar et al.'s (2014) participants identified that the timing of help and support is crucial; they felt that support in the early stages was unnecessary, but later into their parent's illness they wanted more involvement with professionals.

Several studies identified a need for information and guidance. Children often felt that they needed more information in relation to their parent's diagnosis, particularly in the early stages of the illness when they were noticing changes in their parent. In addition, one study reported children's wish to receive practical guidance: *"Especially in the beginning, you do not know how to handle certain situations [...] Some guidance would have been welcome."* (Millenaar et al., 2014, p.2006). Some studies talked about the need for more public information about dementia to reduce the discrimination that results from others not understanding: *"What I wish today, is that everyone just had to know what dementia is. That you should grow up knowing that it is an illness. So that you do not have to be ashamed."* (Barca et al., 2014, p.1941).

1.5. Discussion

Overall, findings from all 16 reviewed studies were remarkably similar, and the refutational synthesis found only two differences: the experience of "positive emotions" in relation to parental YOD (Nichols et al., 2013), though this may form part of the positive aspects of the caregiving role identified in other studies; and the experience of a parent remaining in the parental role (as opposed to reversing parent-child roles), though with confusion as to the child's age (Hall & Sikes, 2016). However, this was still experienced as a *Change in Relationship* and therefore did not alter the subthemes.

The present review aimed to address three questions, each of which will now be explored in relation to existing relevant literature.

1.5.1. What is the experience of children of people with YOD?

The present review produced a 'line of argument' synthesis (Noblitt & Hare, 1988), explaining the experience of having a parent with YOD. Children experience changes in their parent and in their relationships, which have a significant psychological impact, affecting their feelings towards themselves and others. These changes in their parent and the resulting feelings cause practical difficulties in children's day-to-day lives, leading them to make changes to their daily life and also to their life plans. Children have unique and specific needs for different types of support at different stages of their parent's illness.

One of the key findings from the present review in terms of children's experiences was that of grief and loss. The experience of grief in dementia caregivers in general is well established in the literature. Grief has been identified in the early stages after diagnosis (Garand et al., 2012), throughout the illness (Dupuis, 2002; Ott, Sanders & Kelber, 2007) and after the death of the person with dementia (Collins, Liken, King & Kokinakis, 1993; Schulz, Boerner, Shear, Zhang & Gitlin, 2006). There is some evidence to suggest that adult-children and spouses of people with dementia experience grief differently (Meuser & Marwit, 2001; Ott et al., 2007), with children experiencing relief and less grief than spouses when the person with dementia moved to a care-home, and children employing avoidance and denial in the early stages, in comparison to spouses' sadness and reality-focus.

These findings are in line with those from the present review. Children reported grief at different stages of the illness, and spoke of anticipatory grief in the form of waiting for their parent to die. The subtheme of Changes to Relationships also encompasses the sense of "losing" the parent with dementia. Children spoke about avoidant coping strategies, though also discussed a number of appraisal-based

strategies, which may reflect those children whose parents were at a later stage of the illness, or may indicate a difference in younger children's coping compared to the adult-children in the dementia grief literature. Johannessen et al.'s (2016) follow-up study supports the finding that children experience relief at their parent's care-home placement, as children's wellbeing increased with physical and psychological distance from their parent.

1.5.2. What is the impact of YOD on children's psychosocial wellbeing?

Parental YOD was found to have a significant impact on children's psychosocial wellbeing, as evidenced in the theme 'Psychological Impact' as well as subthemes *Changes in Relationships* and *Adapting*. However, in order to fully explore this question it is useful to compare the experiences of parental YOD with those of parental late onset dementia (LOD), in order to identify aspects of the psychosocial impact of parental dementia that are unique to YOD.

Interestingly, the literature relating to experiences of parental LOD is largely quantitative and therefore difficult to compare to the findings of the present review. However, studies have reported that adult-children of people with LOD experience similar elements of psychological impact as reported in the present review, including anxiety and depression (Dura, Stukenberg & Kiecolt-Glaser, 1991; Pinquart & Sörensen, 2011; Wang et al., 2011), guilt (Meuser & Marwit, 2001), as well as grief responses, as detailed above. Changes to relationships have also been reported in the LOD literature, including impact on friendships and marital relationships as well as the parent-child relationship, consistent with findings in the present review (McDonnell & Ryan, 2014; Meuser & Marwit, 2001; Ward-Griffin, Oudshoorn, Clark & Bol, 2007). Additionally, adult-children have been found to experience personal growth as a result of caring for a parent with LOD (Ott et al., 2007), consistent with findings on positive aspects of caregiving reported in the present review.

It is possible, therefore, that many aspects of children's experiences of parental dementia are similar for both LOD and YOD. However, the present review highlighted a number of elements that may be unique to parental YOD. The first is the significance of the parent's young age in terms of other people's lack of understanding and lack of appropriate support; the social impact on children. Children in the present review reported others struggling to understand how someone can have dementia at such a young age, therefore invalidating their own caring experiences and adding to their distress. This is in line with the observation that YOD "is 'out of time' with people's expectations and hopes." (Greenwood & Smith, 2016, p.105). In terms of support, a review of the literature on caregivers' use of services for LOD found the main reasons for low levels of service uptake were that caregivers felt they did not need services or were reluctant to access them; service availability was not a major factor in the decision (Brodaty, Thomson, Thompson & Fine, 2005). In contrast, participants in the present review reported that services were not appropriate for their young parent, despite a desire to access them.

The second difference is the heightened genetic risk in YOD, which contributed to the psychological distress of participants in the present review in terms of worry for themselves in the future; the younger a person is diagnosed with dementia, the more likely their dementia is hereditary. Thirdly, although there were some adult-children in the reviewed studies, the majority of the participants were aged under 25. Those who were older were often reflecting retrospectively on experiences from their teens. In contrast, the majority of studies in the LOD literature appear to involve only adult participants, with the average age of children in a meta-analysis being 51.08 years (Pinquart & Sörensen, 2011). This has important implications for children's support needs, discussed below.

1.5.3. What support needs do children of people with YOD have?

The unique experience of children of people with YOD gives rise to a unique set of support needs. For example, the younger age of most children of parents with YOD

means the parental changes occur at a time when children's identity and increasing independence tend to be the most salient concerns (Erikson, 1968). A synthesis of the literature on young carers' experiences found that caring became an important part of adolescents' emerging identity, which helped to reduce feelings of guilt and anxiety (Rose & Cohen, 2010). This may therefore be one way in which some adolescents resolve the impact on their identity associated with caring for a parent with YOD. Adolescents may have particular needs for emotional support in order to safely explore their identity and independence in the context of their caring role.

In contrast, relationships and commitment tend to be the focus for young adults (Erikson, 1968), and indeed adult-children seemed to place particular importance on the need for supportive relationships and the achievement of some distance from the parental situation (Aslett et al., 2017; Barca et al., 2014; Johannessen et al., 2016). It may be harder for younger children and adolescents to achieve the same level of psychological and physical distance from their parent when they are still financially and emotionally dependent. However, adult-children had additional commitments that impacted upon their caring role and levels of stress, such as their own children or university work. These older children may therefore need more practical support to help them juggle their responsibilities.

Unfortunately, none of the reviewed studies provided findings from only younger children (under 11), so it is not possible to identify any unique experiences or needs of this age group, though some studies did allude to differences in the experience of younger children who had "grown up" with dementia as something they had always known (Hall & Sikes, 2016; Svanberg et al., 2010) compared to those who had experienced a clear change in their parent. It is not clear, however, how this might influence younger children's support needs and further research is needed to address this question for the younger age group.

1.5.4. Limitations

A limitation of the existing literature on young people's experiences of parental YOD is the reliance on the same datasets for a number of different papers; eight of the 16 papers arose from just two sets of data (plus two papers involving separate interviews with the same people), with six papers coming from just one study (Hall & Sikes 2016, 2017, 2018; Sikes & Hall, 2017, 2018a, 2018b). Whilst the authors took a different focus to the reporting of findings, this biases the literature towards the experiences of just one group of young people and one interviewer's questions. This may have particular relevance to the subtheme *Changes in Parent* and the grief elements of *Personal*, to which these papers made significant contributions. Nevertheless, care has been taken in the present review to report on findings from these six papers in the context of a single study, and to ensure that all final themes and subthemes were common across all 16 papers.

In addition, the present review only considered studies that were published in English, and all took place in Western countries. Caregiving experiences cannot be assumed to be the same across cultures, and indeed important differences have been raised in terms of expectations of children caring for relatives between Western and non-Western cultures (e.g. Connell & Gibson, 1997; Lee & Sung, 1997; Robson, 2004). With this in mind, subthemes of *Changes in Relationships*, *Interpersonal* and the main theme 'Needs for Support' may have been different had the studies taken place in non-Western cultures. Findings from this review are therefore only applicable to Western cultures.

1.5.5. Clinical Implications

Despite some similarities to other caregivers, it is important to recognise that there are unique aspects of the experience of having a parent with YOD, which may influence the needs of this distinct group of young people.

Information was identified as a key need, particularly in relation to the parent's diagnosis and guidance on managing particular situations. Several websites exist

specifically for children of people with dementia, which can provide valuable sources of support (e.g. Dementia Australia, n.d.; Nichols & Chow, 2011).

Professionals working with families affected by dementia should be aware of them and be able to direct children towards them. Professionals should be mindful, however, of the content of information they provide to children, as many dementia resources aimed at children are geared towards those with elderly relatives with dementia, not young parents. Information provided by services should take into consideration the experiences of young people as detailed in the literature, and ideally be developed in collaboration with young people themselves.

As well as information for the children themselves, participants highlighted the need for more public information in relation to YOD and its impact on children. Dementia is an international public health priority, and public awareness forms a key part of many countries' dementia policies and strategies (WHO, 2012). However, YOD may be overlooked and a need for greater awareness remains (Young Dementia UK, 2019). Policies should recommend that services specifically ask their clients about children when diagnosing dementia, particularly YOD, and public awareness campaigns should include YOD as a specific element. Schools and professionals working with children in general may benefit from educational programmes in relation to dementia and its impact on children, such as the Kids4Dementia Program in Australia (Centre for Healthy Brain Ageing, 2018).

Services for younger people with dementia are often unavailable or widely spread geographically (Alzheimer's Society, 2015). The present review identified the lack of appropriate services and difficulty accessing them as additional stressors for children of a parent with YOD. Policy makers and service commissioners should be aware of recommendations by groups such as the Young Dementia Network (2016) when considering dementia services, in order to ensure that they meet the needs of younger people and their families as well as older people with dementia. Additionally, services need to empower children to access and influence services on behalf of their parent.

Many participants in the present review voiced the need for opportunities to meet other people in the same situation. Support groups can allow people to feel that they are not alone in what they are going through and to learn from others who have experienced similar situations (Breuer & Barker, 2015; Gonyea, 1989; Solomon, Pistrang & Barker, 2001). Support for relatives and caregivers is a key aspect of dementia care and policy internationally (WHO, 2012), but this often targeted towards spouses or adult caregivers and may be inappropriate or inapplicable to children. Specialist support for children is limited at present (National Children's Bureau, 2016). Dementia services are perhaps best placed to understand the challenges specific to YOD, however, children of people with YOD have much in common with other young carers. A collaboration between dementia services and young carer services is therefore recommended in order to provide tailored and targeted support for this younger subset of children.

1.5.6. Research Implications

Only one mixed-methods study was found for the present review, with the remainder using qualitative methodology. However, the quantitative element of Svanberg et al. (2010) contributed concepts such as caregiver burden and quantifiable measures of resilience and mood disorders, which did not arise in the qualitative data. Future studies may benefit from the inclusion of quantitative methodologies, for example comparing psychological outcomes between older and younger children, between children and spousal caregivers, or between children of YOD and of people with other mental or physical illnesses.

It was not possible to determine any unique experiences of children of different age groups, particularly those under 11, in the present review. Future research might wish to employ stricter age-related criteria in order to explore experiences of younger children. Additionally, the impact of the child's gender was unclear, though has been raised as an influencing factor in young carers' experiences (Eley, 2004) and may therefore warrant further exploration in relation to parental YOD.

1.6. Conclusion

The present review has identified similarities to the experiences of other caregivers but has also highlighted the unique aspects of children's experiences of parental YOD. Children are experiencing the gradual and ongoing loss of their parent at an age where they are also developing their own identity and sense of self. They experience struggles to access services, both because of a lack of available support for YOD in general, and because their needs are different to spouses and adult caregivers. Children need to be empowered in their caregiving roles with the right information and opportunities, so that they can make choices for themselves and their parent with YOD.

Strengths of the present review include the development of second- and third-order themes that synthesise the existing literature and produce a line of argument detailing the experience of children whose parents have YOD. The systematic approach to literature searching has ensured that all relevant literature that meets the inclusion criteria has been reviewed, and tentative recommendations have been suggested in relation to future practice, policy and research.

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Chapter 2: Empirical Paper

Living alone with dementia: A grounded theory study.

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2.1. Abstract

Approximately one third of people with dementia are thought to live alone. Living alone with dementia poses unique challenges and is associated with higher levels of risk and unmet need. However, little is known about the experience of living alone with dementia and, currently, no theoretical model exists to explain the phenomenon. The present study sought to understand how people live alone with dementia. In-depth interviews and grounded theory methodology were used to explore the experiences of people aged between 60 and 88 who live alone and have a diagnosis of dementia ($n=7$), and their friends or family members ($n=7$). A theoretical model was constructed to explain the experience of living alone with dementia. Central to the model are 'core' experiences that directly influence living alone with dementia: *Coping* and *Helping*. Experiences of *Welcome Aloneness* and *Unwelcome Aloneness* result from living alone with dementia. 'Contextual' factors surround the 'core' categories: *Navigating the Diagnosis* leads to *Experiencing Dementia*, which in turn leads to the *Impact on Self* and *Impact on Others*. These then *Impact on Roles and Relationships* reciprocally. *Future-Focussed Concerns* form the 'temporal' level of the model, which both surrounds and permeates the other levels of the model. The present study is the first to present a data-grounded theoretical model of living alone with dementia. Findings are discussed in relation to literature on living alone in older age and having dementia more generally, and clinical and research recommendations are made.

(Word count: 240)

Key words: dementia, living alone, grounded theory, experiences, caregivers

2.2. Introduction

2.2.1. Background

Dementia is an umbrella term for a range of progressive neurological conditions, characterised by loss of function in multiple cognitive domains (Clare, 2008). It is estimated that around 850,000 people in the United Kingdom (UK) are currently living with dementia (Alzheimer's Society, 2017). Rates of dementia are increasing rapidly, and it is expected that there will be around one million people in the UK with dementia by 2025 and two million by 2050 (Prince et al., 2014). As well as the human impact on quality of life and an increased likelihood of earlier death, the financial cost of dementia to society is huge; an estimated £23.6billion in the UK in 2014 and predicted £59.4billion by 2050 (Lewis, Karlsberg Schaffer, Sussex, O'Neill & Cockcroft, 2014). Dementia is therefore an issue of national and global concern with wide-reaching impact.

The present study is concerned with understanding how people live alone with dementia. Living alone with dementia has been defined as a person with dementia living in a single occupant household without full-time support (Ebly, Hogan & Rockwood, 1999; Eichler et al., 2016). Community studies have found that around one-third of people with dementia live on their own (Ebly, et al., 1999; Sibley et al., 2002; Schneider et al., 2002), though these figures may be even higher, as cognitive impairment is more likely to go unnoticed by physicians and family in people living alone (Lehmann, Black, Shore, Kasper & Rabins, 2010). Moreover, there is an international trend of increasing numbers of older people, particularly women, living alone (United Nations, 2005). In line with this, the number of people with dementia living alone is also likely to increase in the future.

People with dementia who live alone are significantly older than those who live with others, more likely to be female, and more likely to be cared for by adult children rather than a spouse (Miranda-Castillo, Woods & Orrell, 2010). They have higher levels of unmet needs, in particular in the domains of thinking and memory,

community living and housework (Meaney, Croke & Kirby, 2005), and are significantly more at risk in the areas of nutrition, money management, medication management, hygiene, fire and falls (Tuokko, MacCourt & Heath, 1999). However, despite the potential risks, the majority of older people prefer to remain in their own home and “ageing in place” is a key component of policy in the UK, being beneficial both for care costs and quality of life (Sixsmith & Sixsmith, 2008).

In order for people to continue living alone as their dementia progresses, increasing levels of support are likely to be needed. It is recognised that people who live alone with dementia are a unique subpopulation requiring targeted interventions (Nourhashemi, Amouyal-Barkate, Gillette-Guyonnet, Cantet & Vellas, 2005). Therefore, it is essential to seek the perspective of people with dementia who live alone in order to gain a deeper understanding of the phenomenon, which can better inform services designed to support them.

2.2.2. Previous Research

Whilst much of the research to date has been quantitative, there are several qualitative studies that have begun to explore the experience of living alone with dementia.

For example, a grounded theory study of people living alone with dementia in the USA found that most of the 15 participants felt comfortable living alone and wanted to maintain this as long as possible, while they also reported not wanting to be a burden on others (Harris, 2006). Elsewhere, content analysis of interviews with 19 people with dementia living alone revealed five themes, relating to life alone, social support, purpose and identity, risk and support strategies (Duane, Brasher & Koch, 2011). Svanstrom & Sundler (2015) interviewed six people with dementia in Sweden who were living alone but dependent on care services. Their findings suggested that living alone with dementia gradually fragments people’s existence so that they lose their sense of identity.

In separate analyses of a single dataset, De Witt, Ploeg & Black (2009, 2010) explored the spatial and temporal experience of living alone with dementia. They interviewed eight women with dementia living alone in Canada, taking a phenomenological approach. 'Living on the threshold' was the overarching experience of the "space and place" aspects, reflecting a sense of being unable to make mistakes. 'Holding Back Time' was the central temporal experience, with medication representing 'Stored Time' by delaying the future 'Dreaded Time', while there was an acknowledgement that living alone had 'Limited Time' and would inevitably have to end.

Finally, Gilmour, Gibson & Campbell (2003) interviewed 10 people with dementia living alone in Northern Ireland, and their supporters, about risk. While no major harm was reported, family and professionals identified risks in several domains, including road safety, money management, falling, cooking and getting lost, whereas the people with dementia reported no risk-related concerns.

2.2.3. Rationale and Aims

The emphasis of the aforementioned studies has been on the experience of living alone with dementia and the associated risks or coping strategies. The majority have taken a phenomenological approach, with one grounded theory and one content analysis study, while none has developed a theoretical model to explain *how* people live alone with dementia. A theoretical model can be particularly beneficial to topics with little existing research (Birks & Mills, 2015), as it can help to explain aspects that are unclear and inform avenues for future research. Whereas existing research has attempted to understand what the experience of living alone with dementia is like, a deeper understanding of how it works at the level of a theoretical model would allow the consideration of other qualitative research findings in light of the model. This, in turn, could help with targeting of interventions and support, as well as making testable predictions about their efficacy.

Only two previous studies have included both people with dementia and family members: Harris (2006) conducted brief telephone interviews with informal carers and Gilmour et al. (2003) interviewed family members about their perception of risk. Harris (2006) did not report findings for family members separately, but Gilmour et al. (2003), demonstrated that participants with dementia and their families had very different views. This difference in perspective has been found in other dementia-related studies (e.g. Huang, Chang, Tang, Chiu & Weng, 2009; Sands, Ferreira, Stewart, Brod & Yaffe, 2004) and highlights the importance of including both perspectives to obtain a full picture of the situation.

Finally, only one study took place in the UK (Gilmour et al., 2003). A representation of the experience of those living alone with dementia in the UK is therefore lacking in the current research literature. It is possible that the different voluntary agencies and healthcare systems of different countries affect the experience of living alone with dementia, meaning that studies are not representative across nations.

The aim of the present study was to establish how people live alone with dementia, incorporating perspectives of both people with dementia and their friends or family members.

2.3. Methods

2.3.1. Design

The present study adopted an interpretivist epistemological position, which assumes that people ascribe meanings to experiences through social interaction, and aims to understand these meanings from the individuals' perspectives (Flick, 2015). Living alone with dementia is by its nature a subjective experience, and therefore appropriate to investigation within an interpretivist framework.

For the present study, a constructivist grounded theory design was employed. Grounded theory is well suited to relatively unexplored topics, such as living alone

with dementia (Birks & Mills, 2015). It aims to create a theoretical model that is “grounded” in empirical material in order to explain a phenomenon (Flick, 2014). A constructivist approach to grounded theory, described by Charmaz (2016), assumes that theory is constructed through the research process rather than being discovered in the data.

2.3.2. Participants

Participants fell into two groups: people with dementia, and “informants”, or people who know the person with dementia well. Seven people with dementia and seven informants took part in the study. Pseudonyms have been used throughout but are not included alongside demographic data in order to preserve participant anonymity. All seven participants with dementia were female, aged between 60 and 88 years, and all lived alone in private accommodation. Dementia diagnoses were Vascular Dementia (3; 43%), Alzheimer’s Disease (2; 29%), Lewy Body Dementia (1; 14%) and Atypical Dementia (1; 14%) and time since diagnosis ranged from 9 months to 8 years. Six of the informants were female (86%) and one was male (14%). Informants were aged between 33 and 68 years. Informant relationships were adult-child (3; 43%), friend (2; 29%), daughter-in-law (1; 14%) and paid supporter (1; 14%).

See Table 2.1. for inclusion and exclusion criteria.

Table 2.1.

Inclusion and exclusion criteria for person with dementia and informant.

Characteristic	Inclusion criteria	Exclusion criteria
<i>Person with dementia</i>		
Age	55-100 years old	Under 55
Diagnosis	Dementia diagnosis confirmed by participant or gatekeeper	Diagnosis of “Mild Cognitive Impairment” (MCI) or no diagnosis
Living situation	Lives alone	Lives with others or has overnight live-in care.

<i>Informant</i>		
Familiarity	Self-identifies as knowing the person with dementia well	Does not identify themselves as knowing the person with dementia well
Contact	Weekly telephone or face-to-face contact with participant with dementia	No regular contact with person with dementia

A lower age cut-off of 55 was selected to align with existing literature and allow for people with younger-onset dementia (below 65) to be captured. Participants were required to confirm a diagnosis of any type of dementia, with the exclusion of “Mild Cognitive Impairment” (MCI), which can be thought of as a separate condition, as many cases do not progress to dementia (Mitchell & Shiri-Feshki, 2009).

Participants were required to live alone with no overnight or live-in care, though they might receive support during the day. Informants were required to have weekly contact with the person with dementia in order to ensure their ability to comment on the participant’s day-to-day functioning, and needed to self-identify as “knowing the person with dementia well”, as the person themselves would have nominated the informant.

2.3.3. Procedure

Participants were recruited in dyads, starting with the person with dementia. A combination of non-probability sampling methods were used; purposive sampling for the person with dementia, and snowball sampling for informants. Non-probability sampling is common in qualitative research and involves deliberately selecting participants who meet certain criteria, rather than randomly sampling from the population (Ritchie, Lewis & Elam, 2003).

As far as possible, the principle of theoretical sampling was used to select participants who could best contribute to the developing theory, in line with grounded theory methodology (Glaser & Strauss, 1967). This maximised the variation in participant characteristics within the pre-defined criteria. Recruitment

ended at the point of theoretical saturation; by the sixth dyad, no new themes or topics were emerging. One further dyad was then recruited to confirm that the information was the same, and it was assumed that saturation had now been reached.

Participants with dementia were recruited via three sources; a West Midlands NHS Trust; a voluntary-funded dementia support group; and a national online database of people with dementia volunteering to take part in research. Participants from the NHS trust and support group were initially approached by a gatekeeper and provided with verbal information about the study. Those who were interested in participating gave permission for the researcher to contact them. The researcher then telephoned the participant to explain more about the study and arrange an interview, and all participants were provided with the Participant Information Sheet by email or post before the interview date. Three participants were recruited in this way.

Volunteers on the online database were contacted directly by the researcher by their preferred method of contact, as the registration process had included consent to be contacted. The preferred method of contact was often email but in one case was telephone and in two cases post. Volunteers had identified at registration whether they would prefer to be contacted themselves or whether they would prefer recruitment to proceed through their named representative, and these preferences were adhered to. A total of 18 volunteers were contacted and four were successfully recruited. Copies of the invitation emails are included in Appendix E.

Once participants with dementia had consented to take part, they were asked to nominate someone with whom they have weekly contact to act as an informant. This allowed access to an otherwise difficult to access group of people, ensured that the person with dementia consented for the informant to talk about them, and ensured the informant knew the participant well enough to comment on their living situation. Participants provided contact details for their informant as part of the

consent process and informants were then contacted directly by the researcher. For one dyad on the online database, both participant and informant were recruited simultaneously due to having contacted the volunteer and their named representative at the same time.

Participants with dementia and informants were interviewed separately in face-to-face, semi-structured in-depth interviews. Interviews took place at a time and place to suit the interviewee, which in all cases was the individual's home. Interview length ranged from 25 minutes to 1 hour 40, and interviews were audio recorded for later transcription. In-depth interviews allow flexibility for pursuing avenues of potential interest, a key element for the development of grounded theory (Charmaz, 2016). Additionally, the semi-structured nature allowed for prompting or further questioning when elaboration was needed, for example when participants went off-topic or struggled to find the right words; common difficulties in dementia.

2.3.4. Materials

An interview guide was constructed for the data collection (Appendix F). Areas for discussion were identified by reviewing previous literature on living alone with dementia. These included positive aspects of living alone, risks and concerns, impact of dementia symptoms, changes or continuity in roles and relationships, and view of the future.

The interview guide was the same for participants with dementia and informants, though informants were prompted to answer with their thoughts about the person with dementia. The interview guide acted as a starting point for discussion of relevant issues, but the format allowed for other topics to arise.

2.3.5. Ethical Considerations

Ethical approval was granted by the Faculty of Health and Life Sciences at Coventry University (Appendix G), and IRAS, the NHS ethics approval process (Appendix H).

The BPS Code of Ethics and Conduct (2009) and Code of Human Research Ethics (2014) were adhered to throughout.

Informed consent was obtained from all participants using specifically designed consent forms (Appendix I, J) and the participant information sheets gave clear and explicit information about the study (Appendix K, L). All participant paperwork was checked by volunteers with dementia in the study's planning stages to ensure accessibility of the writing style and content. Participants were assigned a pseudonym at transcription to ensure anonymity.

Capacity of participants with dementia to consent to taking part was assumed unless there was reasonable cause to believe that they could not understand, weigh up or retain the information in the participant information sheet and consent form, in line with guidance in the Mental Capacity Act (Department of Health, 2005). Additionally, care was taken during debriefing to enquire about participants' feelings following the interview, and to highlight potential sources of support in the debrief form (Appendix M). No participants chose to end the interview early and all had planned contact with friends or family for the same day.

2.3.6. Data analysis

The process of analysis followed the guidance for constructivist grounded theory provided by Charmaz (2016). Constant comparative analysis was used with the interview material (Glaser & Strauss, 1967). This involves making comparisons at each level of analysis, comparing similarities and differences both within and between interviews in order to develop a coherent theoretical model of the phenomenon under study.

Transcripts were initially coded using incident-by-incident coding for actions (rather than topics or themes), which keeps the analysis dynamic and grounded in the original data and ensures that it proceeds from the participant's perspective, by keeping to the actions and meanings they have presented. Each interview transcript

was coded separately, and codes arising from within an individual interview were compared (see Appendix N for initial coding example).

Initial codes were then subjected to focussed coding, which involves comparing and contrasting initial codes both within and across different interviews, and selecting those with the most analytic power, such as the most significant or frequent, to form tentative categories. At this stage, codes were compared both within and between interviews, and focussed codes were formed that subsumed similar codes.

Finally, theoretical codes were constructed, which integrate and determine relationships between focussed codes. Theoretical codes form the deepest and most theoretical level of analysis in grounded theory. They are integrative and give form to the focussed codes, allowing them to take the shape of an explanatory theory.

2.3.7. Reliability

Whilst all transcripts were coded and analysed by the lead researcher, it was considered important to assess the replicability of the coding process, to provide assurance that subjective bias was not having undue influence. A section of an interview transcript was therefore separately coded by an independent researcher.

Of the 56 codes allocated in this segment, 41 (73%) were coded the same by both coders. The percentage of agreement between coders that constitutes an acceptable level of inter-rater reliability is a subject of debate in the literature, however 73% could be considered more than acceptable for the initial coding stage, allowing a reasonable degree of confidence that the coding would be reproducible by a second coder (Campbell, Quincy, Osserman & Pedersen, 2013).

2.3.8. Researcher Reflexivity

The researcher is considered a key part of the qualitative research process, therefore awareness of the impact of one's own background and perceptions is an important consideration (Houghton, Casey, Shaw & Murphy, 2013).

The lead researcher for the present study is a female Trainee Clinical Psychologist who has spent time during training working in a specialist dementia assessment service. During this time, she worked with a number of individuals who were living alone with dementia, many of whom appeared to be coping very well despite their families' frustrations. It is acknowledged, therefore, that she approached the research with prior assumptions as to the differing views of people with dementia and family members, and with an expectation of some positive aspects of living alone arising from the data. These assumptions may have influenced the process of interviewing and data analysis. To mitigate these influences, the researcher kept a reflective research diary during the conduct of the research project, and received close supervision with an experienced supervisory team throughout.

2.4. Results

2.4.1. The model

A three-level theoretical model was constructed to explain the experience of living alone with dementia. Responses of both participants with dementia and informants contributed to all categories.

Central to the model are 'core' experiences that directly influence living alone with dementia. These include the person themselves *Coping* and other people *Helping*, with experiences of *Welcome Aloneness* and *Unwelcome Aloneness* resulting from living alone with dementia.

Surrounding the core categories are 'contextual' factors related to dementia itself. The permeable barrier (represented by a broken line) indicates that contextual-

level factors are constantly influencing the experience of living alone with dementia, as well as interacting with each other. *Navigating the Diagnosis* leads to *Experiencing Dementia*, which in turn leads to the *Impact on Self* and *Impact on Others*. These then reciprocally *Impact on Roles and Relationships*.

The outer 'temporal' level represents *Future-Focussed Concerns*, which both permeate and influence the other levels of the model.

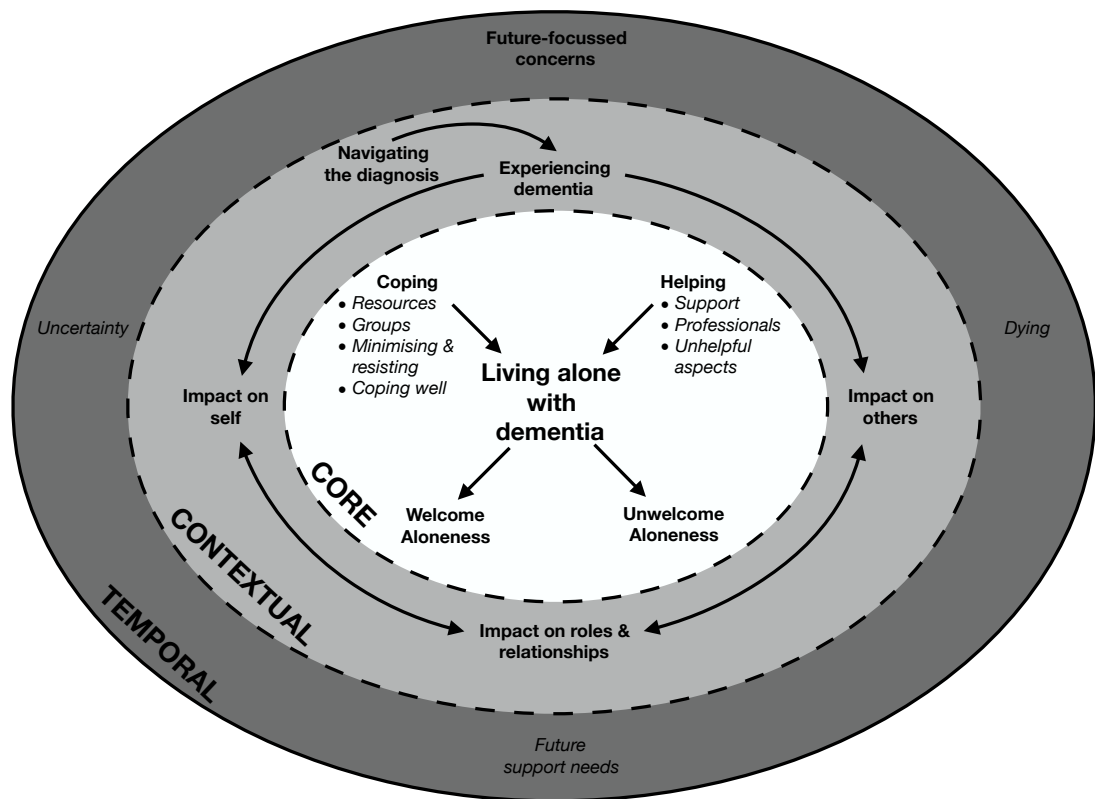


Figure 2.1. Theoretical model of living alone with dementia

2.4.2. Core Categories

2.4.2.1. *Coping*

Participants with dementia and informants both discussed things the person themselves does to cope with dementia-related difficulties. These were strategies,

activities and attitudes that the person adopted specifically to manage the changes that dementia had brought about, in the context of living alone.

RESOURCES

Practical solutions mentioned by both groups included keeping routines, using diaries and notes as reminders, taking a break or doing something different, taking time, planning ahead, and using aids and equipment such as date clocks, whiteboards, key safes and smartphones. Both groups also mentioned the person using strategies to maintain their current level of functioning such as doing crosswords and puzzles “...to keep her brain active” [Informant 4 (I4)], or “*Just testing myself. To see if it’s still there.*” [Participant 7 (P7)]. Additionally, exercise was felt to be beneficial to mental alertness.

Both groups also mentioned emotional and psychological strategies the person uses; for example, laughing about their difficulties: “...that would help anybody to cope with it I think, [...] you can laugh at yourself...without taking yourself too seriously” [I1]. Taking things day-by-day, adapting how they do things, and accepting the new version of who they are were also helpful: “...just do it to what you can now, you know...this is the new you, forget the old you” [P5]. Additionally, some found avoidance to be a helpful strategy at times:

“...the minute you go downstairs into the bigger world then...you’ve gotta work out...you know, putting your tablets out, feeding the dogs...the birds. [...] But if you’re in your bedroom...which it’s a nice bedroom and it’s got coffee and tea and a kettle and...everything up there...then that’s my little comfort zone...my...retreat really.” [P1].

The groups differed on their discussion of inner resources. Whereas informants mentioned personal qualities such as creativeness: “*There’s a creative side to her [...] so there’s a real [...] resource there which stabilises her and gives her mind time to do what it needs to do.*” [I1], participants with dementia spoke about a process of problem-solving:

“...tell yourself what you’re doing. Analyse it in your head and if it doesn’t seem right...then it’s probably not.” [P4].

Although both groups talked about social resources such as asking for help when needed, informants also mentioned the person getting information about services and support, and handing over responsibilities to others; *“...she gives me all the correspondence and says you know, here, is this alright?” [I6].* In contrast, participants talked about how helping others helps them to cope:

“I think it’s...like doing this [research]. I can’t do much for myself, I know...I know...the track that my deterioration will take...but hopefully it will do things for people in the future.” [P1].

GROUPS

Several participants and informants mentioned the person attending dementia-related groups. They said these are enjoyable, offer help and advice, and in particular, allow them to benefit from meeting others in the same situation:

*“...it’s like all the **silly** things that happen to you...you sort of mention it and they go oh yeah that happens to us.” [P5].*

*“I think it’s about being with like-minded people, people who actually will understand her. [...] It makes her feel **part of** something.” [I3].*

MINIMISING AND RESISTING

An additional element of coping included resisting help from others. Participants with dementia discussed many reasons for resisting help, including not wanting to do what was being suggested, wanting to maintain their own skills and not rely on others, or because *“...in asking...you’ve got to admit...your failings.” [P1].*

Participants additionally talked about a fear of being a “burden” to others:

“And then, if you’re having a bad day [...] I’m not gonna burden my son with that. [...] ...he says...oh mum why didn’t you phone me...well why should I...you’ve got your life to live.” [P1].

For participants, therefore, resisting help allowed them to maintain a sense of themselves as coping well. Minimising or hiding their diagnosis from others had the same effect: *“...I don’t know that I want everybody to know, you know, oh that lady who lives there...yet.” [P7].*

In contrast, whilst informants cited similar reasons for the person with dementia resisting help, their perception was often that this was an unhelpful way of managing; *“...but every week we have to go through that oh I don’t want to be a bother. And sometimes you’d just rather...you know, **help** her. And for her to accept the help.” [I5].* Similarly, informants talked about the person with dementia minimising or being unaware of how dementia affects them, again with the implication that this was problematic: *“...she’ll tell people she’s got Alzheimer’s but she doesn’t...understand what that means for her...really. She doesn’t accept what her limitations are at all.” [I2].*

COPING WELL

Despite some disagreement on the helpfulness of certain coping strategies, both groups talked about indications that the person was coping well with living alone with dementia.

Participants mentioned being used to dementia, feeling happy and content and being unconcerned about difficulties: *“To be honest, none of that [forgetting] bothers me.” [P6].* They also felt they were still able to do many of the things they considered important: *“So there are things I can’t do but otherwise, the garden...washing, ironing, cleaning...I...you know, I’m still...at the **moment** capable of doing them.” [P7].*

Informants discussed more observable signs of the person coping well, such as keeping up with household tasks, maintaining their positive outlook, and being aware of their difficulties. One informant mentioned the person's attitude towards dementia as an asset: *"She's just...fighting it really, she's not going to let it get to her."* [14]. Several informants also spoke about the person with dementia appearing very well, such that it's not obvious that they have any difficulties: *"But the fact that she's had it ten years, I mean...she really does very well. You wouldn't **know** she had it."* [17].

2.4.2.2. *Helping*

Both groups discussed ways in which other people support the person with dementia. As with *Coping*, this category described things that people do with the intention of helping, specifically because of the person's dementia and their context of living alone. This also covered aspects of people's responses that are considered unhelpful.

SUPPORT

Some of the practical support that both groups mentioned included being patient and understanding, helping with practical things such as cleaning and giving lifts to places, providing aids and equipment, and taking the lead when needed.

Different degrees of practical support were discussed by informants: promoting the person's independence, supervising the person, taking over responsibility for tasks, preventing them from doing dangerous things, and putting support in place despite resistance:

"So now I've decided we just have to do things and...you know...just essentially force her to go with it and she comes round." [12].

Conversely, one informant talked about deliberately not helping in order to encourage the person to help themselves; *"...like if she's in the middle of a sentence*

and she's forgotten a word...I tend to not help her and just let her get the word on her own." [I5]).

Emotional support mentioned by participants with dementia included people making an effort to spend time with them, and simply letting them know and feel that help is available:

"My daughter in law phones me every day, see if I'm alright. [...] And I've got this lifeline...so I only have to press that button, and then they come through on the recorder saying what can we help you with, are you alright." [P4].

Informants mentioned talking together about dementia and the future, and advocacy roles such as helping others to understand the person's difficulties and working with others to coordinate support for the person with dementia.

PROFESSIONALS

Participants with dementia and informants differed in their views on what is helpful from services and professionals. People with dementia appreciated professionals being accessible and taking their decisions seriously; *"And...I am pleased that...official people have taken that on board. That they haven't poo-pooed it or tried to change my mind or anything."* [P1]. Conversely, informants discussed the importance of having the right support in place, professionals helping with plans for the future such as Power of Attorney, and services supporting the person with dementia's independence. Additionally, informants mentioned accessing support for themselves as carers.

In terms of unhelpful aspects of services, both groups agreed that support changing or ending is very difficult, and both discussed difficulties finding support appropriate for younger people or earlier stages of dementia. Conversely, several participants and informants reported the person feeling *"overwhelmed with support"* [P5] when too many services were involved at once.

UNHELPFUL ASPECTS

Participants with dementia also talked about some of the things that friends, family and members of the public do which they find unhelpful. Examples included being insensitive, such as telling them how long they might live, rushing them and making them feel self-conscious about their dementia. Additionally, some participants talked about well-intentioned support that was sometimes experienced as too much, such as checking on them too often or panicking if they didn't reply straight away to messages. Both groups talked about others not understanding the person's difficulties or the gravity of their diagnosis.

2.4.2.3. *Welcome and Unwelcome Aloneness*

The core experience of living alone with dementia resulted in two types of "aloneness", where a distinction was drawn between positive and negative aspects of living alone. This was not a straightforward either/or experience; the majority of participants experienced some degree of both types.

All participants and informants mentioned some element of the person being able to remain independent and do things for themselves: *"So...easier...[sic] not someone stepping in or getting cross."* [P3]. Additionally, both groups talked about the person doing what they want, enjoying their own company, retaining control over their environment and making their own decisions.

Several participants with dementia reported feeling comfortable living alone. Similarly, several informants said they currently had no concerns about the person with dementia living alone.

However, both participants and informants discussed the person feeling lonely and feeling worried about being alone. Participants with dementia added that living alone means they have nobody on-hand to help out or remind them of things: *"...there's nobody to bounce off...there's nobody to say...oh you'll never guess, I*

haven't got a clue here...oh well, here's what you do...so it lingers with you. It stays with you." [P1].

Some participants and informants also distinguished between living alone though with family nearby, and living completely alone:

"I think if you were on your own and you didn't have kids or you didn't live near any family it would be a lot more horrible." [I5].

2.4.3. Contextual Influences

2.4.3.1. *Navigating the Diagnosis*

Several of the participants with dementia spoke in detail about the long process involved in getting to the right diagnosis, from noticing changes in themselves, through getting a number of different (incorrect) diagnoses and having tests and scans: *"But I've been seeing a neurologist for twenty years...and every time I saw one it was a different diagnosis."* [P5]. Informants also mentioned the long process and difficulty adapting to diagnostic changes: *"Her diagnosis as I'm sure you know has changed over time...so emotionally she's been through a bit of a rollercoaster there..."* [I3].

Receiving the diagnosis of dementia was experienced by some participants and informants as a relief, the end to a long process and finally having a name for the changes they had noticed. However, for some participants with dementia, being given the diagnosis left them feeling overwhelmed and without support: *"So people don't take on board that being given a diagnosis of dementia is...as much as cancer is, you're given a death sentence."* [P1].

Some participants with dementia described an ongoing process of trying to make sense of their diagnosis. They expressed a preference for an illness that would be easier to understand: *"I'd rather have a physical illness...than a mental illness. [...] It seems more...you can understand it more."* [P7]. Participants also described

gradually coming to terms with their diagnosis and what it meant for them, including feeling as though their retirement had been stolen by dementia.

2.4.3.2. *Experiencing Dementia*

The diagnosis led to dementia-related changes, and these were discussed in detail by most participants and informants. Changes commonly mentioned by both groups included the person getting confused or lost, forgetting words, repeating themselves, losing their train of thought, and forgetting how to do things.

Several participants and informants talked about the person unintentionally putting themselves in danger, often when cooking:

“...you’ll have something cooking in the frying pan...but like an idiot you’ve still got to put your fingers in it to see if it’s hot.” [P1].

“...she’s a danger to everybody if she cooks. Um she’s had the fire brigade out multiple times.” [I2].

Some experiences were more specific to individuals, and were mentioned by the person themselves and their corresponding informant; for example hallucinating, difficulties with planning and organising, finding speaking effortful and tiring, and having “*blank spells*” [P7] where the person was unable to respond for several minutes.

Informants discussed additional difficulties they had noticed, such as the person neglecting to wash and eat, struggling with change and having variation in their abilities: *“I suppose it’s like fog and sun. So, some days she’s completely clear and sharp as anything. But on a foggy day she’s not so sharp.” [I4].*

Some informants also spoke about the person with dementia being unaware that they were losing their sensory abilities, which could put the person in danger or irritate other people:

“...she’s completely oblivious to hot and cold now. So...she was going out in the really cold weather at the start of the year...in a very thin coat without hat and gloves and...not proper footwear on.” [I2].

“...she won’t have her hearing aids on, she doesn’t think she’s deaf. Her eyes aren’t very good but she thinks they are.” [I6].

Many participants and informants also mentioned difficulties with the person’s physical health and sleep. Some participants prioritised these difficulties over those related to dementia; *“Well...my main trouble is not the dementia but the fact that I lose my balance.” [P2].*

2.4.3.3. Impact on Self (Person with Dementia)

People with dementia spoke about the impact that dementia has on them, over and above the symptoms themselves. Informants also discussed the impact on the person with dementia, though tended to focus on observable behavioural consequences, such as the person getting more frustrated:

“I think it’s frustrating for her that she can’t do things. [...] ...she’ll say I know you’ve told me loads of times but I can’t remember...you know. It’s frustrating, yeah.” [I6].

In contrast, participants with dementia talked about feeling defeated and missing out on opportunities due to dementia. Several participants talked about isolating themselves or feeling they should stop activities because of dementia. Additionally, being forced to give up driving was described by one participant as *“the worst day of my life.” [P6].*

“But I know I am becoming reclusive [...] [Professional] explained to me that that’s the brain’s way of coping. Because the brain knows that when I set foot out of here I’m going to be met with conflict, new things etcetera...the brain kind of says...well just stay where you are.” [P1].

“The current affairs group I used to go to...I thought it was my duty to stop, once I’d been...labelled with all these things, I thought I had to stop.” [P6].

Several participants spoke about feeling useless or no longer needed by others due to dementia related-changes:

“...when I first admitted it to my son and my friends I burst out crying. Because it’s hey look how bloody useless I am.” [P1].

*“...and I did go through that feeling...that I wasn’t useful...you know I’d got...I wasn’t **needed** any more.” [P4].*

One participant spoke about the cruelty of dementia: *“The photographs are there but I look at the photographs and think...where were we, what were we doing. But...that’s...it’s...it’s a very **cruel** disease I think.” [P7].*

2.4.3.4. *Impact on Others*

Some participants with dementia and many of the informants talked about the impact of dementia on other people, particularly the person’s children and friends.

Informants expressed worries about the person with dementia’s safety (particularly when driving), the person upsetting or annoying other people, and how best to support them. Some adult-children also worried about their own chances of getting dementia. Participants with dementia acknowledged the same worries in others, and added their concern about the impact on their children of helping them with day-to-day tasks:

*“I don’t think I’m altogether...put this carefully...a burden to her. [...] A nuisance, perhaps. Awkward, yes. [...] But I don’t **think** she would label me as a burden.” [P7].*

Some informants spoke about feeling sad at the situation and at seeing the person with dementia deteriorate. Others talked about their sadness at the things that dementia takes away; *“You start to realise it’s not going to go on forever...and you start to want more time together.”* [I5].

Several participants with dementia noticed others being upset or uncomfortable when they can’t remember things, sometimes feeling they need to pretend for others’ sakes:

“...I think they feel a bit uncomfortable because I know I do forget things. I mean the forgetting doesn’t worry me. But I think it must be embarrassing for other people, in a way.” [P6].

“Occasionally with people I’ll sort of say oh yes as if I do remember, because it’s easier for them [...] to think that you understand. You know, when we did so and so wasn’t it fun...yes it was, it was great.” [P7].

Some participants with dementia spoke about people getting annoyed or irritated with them, for example when they interrupt conversations to say or write down something they need to remember. Informants expressed their own frustration about the person with dementia not asking for help, or conversely, feeling that they had taken advantage of their kindness. They also spoke about the effort involved in supporting the person and frustration about the dementia itself:

*“...but I mean it is frustrating because I don’t understand whether she is doing it deliberately, whether she doesn’t **understand** what I’m saying...”* [I6].

2.4.3.5. *Impact on Roles and Relationships*

Roles and relationships are also impacted by dementia through the impact on self and others. Both groups discussed a change in dynamics between the person and

their children in terms of a “role-reversal” [I2]: *“I think...if you like...I’ve become the daughter and she’s the mother.”* [P6].

Participants with dementia additionally discussed feeling that friendships are no longer equal, having to reassure others or let them help for their benefit, and losing roles they once held:

*“And...because I was a teacher, I was the one who was in charge, you know, telling people what to do and when to do it and looking out for **them** and caring for **them**.”* [P7].

For some informants, obligation was a feature of their relationships:

“...every now and again I just think I can’t be bothered...but you can’t just leave her. So...[crying] just have to battle away at it.” [I2].

*“...I just think she’s given up a lot of her life for **us**...so...you know, the least we can do is like try and repay some of that now.”* [I5].

However, both participants with dementia and informants talked about aspects of continuity in relationships: *“That’s just how we’ve always been I think [laugh].”* [I5].

2.4.4. Temporal Aspects

2.4.4.1. *Future-Focussed Concerns*

All participants and informants talked about some aspect of the future. There was much overlap with other categories, for example the anticipation of future dementia-related changes feeding into the *Impact on Self, Others and Relationships*, and ways of *Coping* and *Helping* taking into account future possibilities or adapting over time. However, *Future-Focussed Concerns* consists of overarching elements of the future of living alone with dementia that surround and permeate all other categories in the model.

UNCERTAINTY

Almost all participants and informants identified the unpredictability and uncertainty of dementia as a key concern:

*“...that’s the hardest bit, you know I try to pin [psychiatrist] down...unfairly really because she doesn’t know...what **is** the prognosis, when will my decline suddenly escalate, will it go on for a long time...we don’t know.” [P7].*

Other uncertainties for both groups included worries about dementia getting worse, having no control over dementia, and further changes to their personality or memory, for example being unable to recognise their children. Both groups reported the person feeling scared or worried at seeing others with more advanced dementia.

Both groups had found ways to cope with their worries such as making plans for the future, though some participants with dementia said that they put off making plans for fear of uncertainty. Both groups also spoke about making the most of the present and not dwelling on the future:

“So...hmm...it’s...faith will be okay [sic] but still...only need now coz ahead is a bit [grimace]” [P3].

“I think you don’t want to start talking about those things unless it’s imminent...I guess it’s in the back of my mind but not...not really a concern at the minute.” [I5].

Some participants with dementia hoped that they would lose awareness of their difficulties as their dementia progressed. In contrast, informants discussed a process of accepting what might happen: *“And...day-by-day we’ll go through it...together.” [I1].*

DYING

Many participants discussed a preference to die before their dementia progressed too far:

"...I have no intention of going in a home or anything. I shall end my own life." [P1].

"I think I'd prefer to...cease the mortal coil in a natural way before I...became...too incapable of anything." [P7].

Informants were also aware of the person's wish to die, and one informant expressed her own fear that her mum might continue to deteriorate for a long time:

"I have a horrible feeling that as there's absolutely nothing else wrong with her she's going to last for ages. And...none of us want that. Because she is...going to hate it. And we are going to hate watching it. It's...I would much rather she had some...heart condition and dropped dead rapidly now than...than have to watch this painful slide" [I2].

FUTURE SUPPORT NEEDS

Both groups discussed worries about future care costs, and several participants with dementia discussed adapting to the idea that they will need more support at some point. Similarly, many informants anticipated a need for more support in the future and worried about how the person with dementia might respond:

*"And...she is going to **hate** having to be helped **so much**." [I2].*

"...it's going to be difficult for her to ask...for practical help I think because she's so fiercely independent." [I1].

2.4.5. Interactions within the Model

In the 'Core' circle, *Coping* and *Helping* feed into the experience of living alone with dementia, whereas *Welcome Aloneness* and *Unwelcome Aloneness* result from living alone with dementia. All participants discussed a complex mix of all four experiences, and it was not possible from this methodology to make any predictions about outcome.

The 'Contextual' circle begins with *Navigating Dementia*, which is a constant process of making sense of the diagnosis. This leads to *Experiencing Dementia* in terms of the changes and symptoms associated with the illness. These changes inevitably affect both the person themselves and the people around them, leading directly to the *Impact on Self* and *Impact on Others*. Because of the effects of dementia on the self and others, roles and relationships are then affected. The *Impact on Roles and Relationships* also feeds back into the *Impact on Self* and *Impact on Others*, as the changes in relationships have further consequences for the person themselves and others around them. All of these elements have an influence on the 'Core' experiences of living alone with dementia, for example isolation (*Impact on Self*) enhancing feelings of *Unwelcome Aloneness*, and frustration (*Impact on Others*) perhaps leading to more unhelpful ways of *Helping*.

Finally, the 'Temporal' circle consists of three aspects of *Future-Focussed Concerns*. These aspects are related but do not have a direct impact on each other; hence there are no arrows in this circle. *Future-Focussed Concerns* impact on all elements of the 'Contextual' and 'Core' circles as they represent overarching threads that are present in all categories.

2.5. Discussion

The present study has produced a data-grounded theoretical model of living alone with dementia, incorporating contextual and temporal aspects as well as experiences specific to living alone with dementia.

Participants with dementia and informants both contributed to all categories within the model, and generally there was agreement between the two groups in terms of the content. Where there was divergence, informants tended to notice observable behavioural consequences of the psychological experiences mentioned by participants with dementia. For example, informants identified people with dementia losing their temper, whereas participants with dementia discussed feeling useless and frustrated with themselves. Whilst all aspects of the model are relevant to understanding how people live alone with dementia, a number of components overlap with concepts found in discussion of the experience of dementia more generally or of living alone in later life (Haslbeck, McCorkle & Schaeffer, 2012; Steeman, de Casterle, Godderis & Grypdonck, 2006). However, two aspects of the model, 'Welcome and Unwelcome Aloneness' and 'Future-Focussed Concerns', stood out as having particular relevance for living alone with dementia and thus merit further consideration here.

The concept of unwelcome aloneness included feelings of loneliness, which is a key focus of many studies of older adults and has been linked to living alone in older age (Victor, Scambler, Bond & Bowling, 2000). However, the concept of unwelcome aloneness also included having nobody around to bounce ideas off or to prompt or remind the person with dementia; aspects which are more specific to having dementia. Studies of couples where one person has dementia have found that spouses play a key role in prompting and reminding (Gillies, 2000), as well as "supervising" by checking on the person and monitoring their safety (Jansson, Nordberg & Grafstrom, 2001). Participants in the present study, however, had to rely on their own ability to self-monitor and use their own initiative in problem solving, suggesting that coping resources and strategies are more important when living alone.

In contrast, welcome aloneness related more to comfort in solitude and satisfaction in having autonomy over activities and schedules, which again are perceived benefits to living alone in older age more generally (Eshbaugh, 2008). However, like unwelcome aloneness, the concept of welcome aloneness also included aspects

more specific to dementia, such as being able to control the environment to suit their needs, doing things at their own pace and retaining skills and independence. Research in nursing homes has demonstrated that caregivers can inadvertently de-skill people with dementia by limiting opportunities for them to do things for themselves, causing “excess disability” (Rogers et al., 2000; Woods, 1999), whereas people with dementia and informants in the present study both felt that skills and abilities were preserved because of the person living alone.

Concerns for the future were found to influence all aspects of living alone with dementia. Given the degenerative nature of the condition, it is unsurprising that concerns for the future are mentioned in much of the dementia literature (Steeman et al., 2006). However, certain aspects may hold additional significance in the context of living alone, as the uncertainty relates not only to the disease progression, but to the continued viability of the living situation itself (de Witt et al., 2010).

For many participants in the present study, the possibility of needing more support was a frightening prospect. Many resisted or refused support, and informants identified concerns about persuading them to accept more support in the future. It has been found that dementia presents a threat to self-identity and the feeling of being valued, which can be restored in part by minimising or denying problems and affirming one’s competencies (Steeman, Godderis, Grypdonck, de Bal & de Casterle, 2007). Independence may therefore form a key aspect of identity when living alone with dementia, so that accepting help presented a significant threat to participants’ sense of who they are. Self-maintaining and self-adjusting strategies for coping with the threat to self (Clare, 2003) were evident throughout participants’ narratives, such as minimising or compensating for the difficulties, and adjusting to changes or “accepting the new me”.

2.5.1. Clinical Implications

The model makes useful suggestions for ways to support people to live alone with dementia successfully. *Coping* and *Helping* both contributed to the core experience of living alone with dementia. Interventions may therefore wish to focus on equipping people with coping resources, and encouraging friends and family to offer support that is experienced as helpful, such as checking-in, spending time together, and enabling the person to help themselves.

Therapeutic work might wish to focus on the psychological impact of dementia, both for people with dementia themselves and those supporting them. Therapeutic approaches that foster acceptance and adjustment to difficulties may be particularly helpful, for example Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 2016), as acceptance formed a key part of emotional coping for both participants and informants. Coming to terms with needing additional support (for people with dementia) and with having offers of support rejected (for informants) may also be useful elements of therapeutic work. Helping informants to understand the motivations behind things they find frustrating such as rejections of support and the person seemingly not understanding or accepting their difficulties supports a person-centred approach, in which caregivers take the person with dementia's perspective (Brooker, 2003). In addition, Compassion Focussed Therapy (Gilbert, 2010) may also be beneficial for people with dementia in helping them to be kinder to themselves in the face of challenges and mistakes, and reduce the impact of "dwelling" on difficulties when alone.

Continuity and coordination were two aspects that contributed to how helpful professional support was perceived to be. In particular, participants struggled when too many services were involved at once, or when supporters changed. Policies and service guidelines should consider people with dementia who live alone as a separate group with unique support needs, and should focus on maintaining independence and identity when offering support. Services need to ensure a coordinated approach and ideally allocate a keyworker who can remain with the

person throughout. Policies and guidelines should ensure that people living alone with dementia are given ample opportunity to discuss and make decisions regarding the future, including considering the implications of further deterioration on their living situation and planning for this.

2.5.2. Research Implications

The present study, and existing research, has taken a cross-sectional approach with interviews conducted at only one time point. Longitudinal research could add a deeper understanding of the process of living alone and how it develops over time and as dementia progresses. Future research may also wish to explore experiences of people who have recently moved into residential or nursing care from living alone, to explore in more detail the challenges of living alone with dementia and factors that cause it to end. The inclusion of observational measures where possible may add an objective element to understanding how people manage day-to-day. Future research may also wish to compare experiences of supporting someone with dementia living alone against living with them.

2.5.3. Limitations

Despite the intention to include both genders, only women with dementia took part in this study. Whilst the majority of people living alone with dementia are female (Mirando-Castillo et al., 2010), the experiences of men may be very different. The findings therefore can only be applied to women living alone with dementia. Additionally, all participants were Caucasian, which may limit the cultural transferability.

The majority of participants with dementia in the present study were in the early stages of their disease, with a good level of insight into their difficulties and the ability to explain their experiences coherently. It is likely that those who are willing and able to participate in research are coping better than those who cannot, and it is possible that those who do not cope well with living alone may move into residential care sooner. The present study, therefore, reflects only those

experiences of people who are currently managing to live alone relatively successfully with dementia.

An additional limitation is the recruitment of informants through the person with dementia; the person may have been more likely to select someone they felt would corroborate their view or present a positive picture of their coping, rather than someone who would disagree with them. However, for the purposes of the present study, it was felt that the ethical consideration of the participant's consent for the informant to talk about them was more important than this potential bias.

2.6. Conclusion

The present study is the first to present a theoretical model of living alone with dementia, incorporating both people with dementia and informants' perspectives. Living alone with dementia is a complex phenomenon that incorporates unique aspects over and above those related to living alone in older age, or to having dementia. Within this model, experiences of welcome and unwelcome aloneness form the 'core' of living alone with dementia, influenced by coping resources and the help of others.

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Chapter 3: Reflective Paper

Personal reflections on conducting research with people with dementia and those who support them.

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3.1. Introduction

The processes of conducting and evaluating research and applying the findings to clinical practice are fundamental to the scientist-practitioner model of clinical psychology, which places research and practice at the heart of the discipline (Page & Stritzke, 2006). However, equally important to clinical psychology is the philosophy of reflective practice, which involves the ability to reflect upon experiences and processes in order to modify and develop practice (Hall & Llewelyn, 2006). The ability to reflect on personal and professional experiences is a core skill of clinical psychologists (Division of Clinical Psychology, 2010) and of health professionals in general (NHS Leadership Academy, 2011).

When reflecting on experiences, it is sometimes useful to use a reflective model as a guide. Gibbs' Reflective Cycle (1988) consists of six stages, presented in a circle to represent the ongoing process of reflection and the continual application of learning from reflection to future situations. The first stage consists of a description of the situation, providing information about what happened, when, where and with whom. Next, the reflector considers the thoughts and feelings that arose for them before, during and after the experience, and then evaluates the positive and negative aspects of the situation. The analysis stage allows the reflector to make sense of the situation and apply a new level of understanding to extract meaning from the experience. This is drawn together into conclusions about the learning that has arisen from the experience, which, in turn, forms an action plan to determine how this learning can be applied in the future.

Reflecting on the research process can lead to new insights about the self and the research topic (England, 1994). Additionally, reflection allows the researcher to recognise their biases and learn more about the group of people under study, continuing the research process and impact long after the study is completed (Bourke, 2014). Throughout my research project, I have kept a reflective journal to record my thoughts and feelings in relation to the research. This is recommended as part of the grounded theory process of keeping research memos (Charmaz,

2016), but keeping a written record of reflections is also recommended as part of reflective practice more generally (Bolton & Delderfield, 2018). Themes drawn from the reflective journal I kept throughout the research process have been used to inform the present reflective chapter. Informed by Gibbs' model, and with implications for future clinical and research practice in mind, this report will detail my reflections at each stage of the research process; from deciding on a topic, through my encounters with participants, to the analysis and compilation of findings.

3.2. Deciding on a Topic

My initial interest in the topic of living alone with dementia stemmed from a professional experience, but over time I also became interested on a personal level. Early into my placement in a specialist dementia assessment service, I attended a talk about a research project into lived experiences of dementia, in which the speaker drew my attention to the lack of research about people who live alone. This sparked my interest because I know a number of older people in my personal life who live alone, though not with dementia. I found myself wondering how they would manage if they were to be diagnosed with dementia, and how their experiences might differ from people who live with spouses. I had very little personal experience with dementia and, perhaps influenced by media coverage of the later stages, had initially assumed that the constant presence of another person would be almost essential after a diagnosis. Indeed, research into public perceptions of dementia has found that the majority of people believe high levels of supervision and reduced autonomy are necessary for all people with dementia (Rosato, Leavey, Cooper, de Cock & Devine, 2019). However, my assumptions were soon challenged as I began to meet numerous people in the early stages of dementia and realised that, for many of those people, much of the time their difficulties were not evident at all.

Later in my placement, I assessed several people who were living alone, and came to understand some of the concerns of their families in relation to their safety.

However, I was surprised to find that the people themselves were not concerned and were actually managing well living alone despite the difficulties that dementia presented to them. For some individuals, living alone was an important part of their identity. I was particularly impressed by how these people had adapted their lives to accommodate and compensate for their changing abilities, and found that working with them served to challenge my belief that living alone with dementia would be risky, difficult and unwelcome.

I began to build up a picture of living alone with dementia which I wanted to explore further. However, I was disappointed in my initial searches of the literature to find that much of the existing research focussed on risks. I struggled to find much in relation to the experience of living alone with dementia, and nothing that explained what makes it possible. I wanted to better understand how my clients were managing to successfully live alone, and what factors might make it possible or difficult for the older people I know, should they ever be diagnosed with dementia. With my clients as inspiration and my older friends as motivation, I decided this would make an ideal topic for my research project.

I encountered a number of different reactions when colleagues, friends and family enquired about my research topic, though most commonly and most surprising to me was the expectation that dementia would be a very sad subject to immerse myself in. This was at odds with the experiences I had had working in the dementia team, where the ethos was very much one of “living well with dementia”, in line with the UK government’s national dementia strategy (Department of Health, 2009). I had experienced the support and opportunities that can arise from a dementia diagnosis, such as activity groups, new friendships and the chance to advocate for policy and service change, and had met people who were managing well in the early stages.

However, experiencing this response from others made me question my initial thoughts and, on reflection, was helpful in adjusting my expectations for the research findings. It is well recognised that researcher bias and prior experience can

influence the process and outcome of qualitative research (Houghton, Casey, Shaw & Murphy, 2013), and recognising early on in the process my hopes or expectations of some positive findings was essential to ensuring that I was able to obtain an authentic picture of the experience of living alone with dementia from my participants. I wondered whether the focus on living well and enjoying life after a dementia diagnosis might invalidate and exclude people who didn't feel that way, and resolved to ensure that my participants would be able to express their feelings either way.

In the process of their research into living with dementia, Steeman, Godderis, Grypdonck, de Bal and de Casterlé (2007) recognised that their approach to interviews had unwittingly influenced participants' responses. By focussing on deficits and challenges, the researchers had made dementia seem unacceptable, and participants responded defensively and focussed only on the positive aspects. I became aware that I might be at risk of doing the opposite and focussing only on positive experiences, therefore I made a conscious effort to ensure that I incorporated a balance of questions into my interview guide. This reflection has implications for my ongoing clinical practice as well; assessments in mental health are often structured around defining and understanding the difficulties, but a much more balanced and nuanced picture can be obtained when asking about strengths and resilience, as well as providing valuable information that can be used to inform intervention plans and, most importantly, ensuring that the client feels understood and empowered (Tedeschi & Kilmer, 2005).

3.3. Research Interviews

As a trainee clinical psychologist interviewing people about living alone with dementia, I was in the "outsider" position, having had no personal experience of being in the situation myself (Berger, 2015). This offers certain advantages over researching a topic in which the researcher is personally immersed; the researcher can bring a fresh perspective and a new viewpoint to a topic, and, most importantly, the participants naturally fall into the "expert" position, which is often

an empowering experience for them (Berger & Malkinson, 2000). Although this is also the case in a therapeutic context, as clients are experts in their own experiences, and often the clinician has not experienced the same difficulties, clinical encounters are by their nature structured around a “problem” for which the client is seeking help. As a clinician, I often feel as though clients place me in the position of “expert”, with an expectation that I will be able to understand, explain and resolve their difficulties. However, as a qualitative researcher I was handing the power over to my participants (England, 1994). This left me feeling simultaneously vulnerable and liberated; I had less control over the situation, but consequently less pressure to deliver any specialist knowledge or insights.

After my initial anxiety at the start of the data collection process, I found I was able to settle into the role of a curious “outsider”, and noticed that I was genuinely interested to hear about my participants’ experiences. I became familiar with my research questions and was able to use them more flexibly and be guided by the participant. This relaxed approach undoubtedly put participants at ease, and indeed several of the participants with dementia commented that they felt I was understanding and easy to talk to, and that the process felt more like a conversation than an interview. When reflecting on the enjoyment and sense of ease I felt when interviewing participants for my research, I realised that the same curious, interested and unhurried approach was likely to be beneficial for my therapeutic clients as well. Indeed, “not-knowing” is an essential aspect of the clinician’s stance in relational therapies (Anderson & Goolishian, 1992). I therefore hope to apply this approach to my future encounters in clinical as well as research settings, and feel it will ease both my own anxiety at the pressure to be “expert” and my clients’ anxiety at the unfamiliarity of the situation.

In my interviews, however, despite the balance of power being in the participants’ favour, I still had a responsibility as a researcher to guide the conversation in the direction of the research questions. I anticipated some difficulty in interviewing people with dementia compared to other groups of people, as dementia-related difficulties such as forgetfulness and language difficulties might get in the way of a

focussed and flowing conversation (Nygard, 2006). I perhaps approached my initial interviews with some increased anxiety about what to expect from participants and how I might manage difficulties in conversation, but was surprised and pleased to find that many of my participants were very willing to talk about their experiences, and the majority were able to speak eloquently and insightfully about living alone with dementia.

I did, however, encounter some challenges during the interviews, the most common being participants going off-track in their conversation, talking about topics that were not relevant to the research or losing their train of thought. I did not wish to invalidate participants by interrupting or redirecting the conversation yet was aware that I was there for a specific purpose. I noticed myself feeling frustrated at times when the conversation was going off-topic and became preoccupied for short periods worrying about how I might get the conversation back on-track rather than focussing on the meaning of the digression for the participant.

Some participants repeated the same stories several times during their interviews and seemed to change the subject when I asked questions specifically about dementia. In hindsight, I wondered whether these participants saw the questions as a challenge to their independence and coping and may have felt that they needed to present or respond in a certain way. Hubbard, Downs and Tester (2003) suggested that their participants' repeated return to the same topic throughout their interviews was an important strategy for managing embarrassment at forgetting and moving the conversation onto more familiar ground, and it seems entirely possible that the same process was operating with my participants. On reflection, whilst I may not have recognised the potential purpose of the change in subject at the time, I feel I managed the situation well. I allowed the participants to redirect the conversation, while still obtaining relevant information by relating what they said back to the present day. For example, I summarised one anecdote about a participants' aunts and uncles by suggesting that family seemed very important to her.

This experience has led me to reflect in more detail upon the experiences of the informants in my study, and those who support people with dementia more generally. My initial reaction to participants' digressions in conversation was frustration that we had deviated from my objectives. However, within this, I had neglected to consider both the participant's experience and their intention in that moment. In the research context, I was a stranger and a professional and therefore able to retain a relatively high degree of objectivity and respond in a way that did not invalidate or dismiss the person. However, I can imagine that family and friends encountering the same situation repeatedly and on a regular basis may struggle to contain similar feelings of frustration and to respond helpfully. Research has found high levels of frustration in caregivers of people with dementia, which is particularly associated with dependence in daily living tasks (Motenko, 1989), and the need for support for caregivers in managing these frustrations has been identified (Gallagher-Thompson & DeVries, 1994). Informants in my study mentioned feeling frustrated at times, and although we did not go into detail on these experiences, I felt able to identify and empathise with how it might feel to support someone, particularly when objectives between the person with dementia and the informant differed.

I wanted to know more about the experiences of informants and experienced a tension between my role as researcher and my usual role of clinician, which was most apparent when interviewing informants compared to people with dementia. I was aware that people with dementia had volunteered to take part in the research and had given consent for me to ask about their experiences, therefore I felt comfortable asking the more personal questions I might ask as a clinician, such as enquiring about their thoughts and feelings, as these were directly relevant to the research aims. The informants, however, had been nominated by the person with dementia and therefore may not have entered quite as enthusiastically into the research. They had consented to speak about their perceptions of their friend or family member's experiences, but I felt as though it was more intrusive to ask them about their own feelings, particularly when it was not willingly offered. I noticed that some informants appeared particularly guarded about their own feelings, most

noticeably the friends and professional supporter as opposed to the adult-children, and felt myself being more cautious around potentially emotive topics such as their thoughts on the person's future and their feelings about the support they offer. As a clinician, I might have probed a little deeper, but I recognised that my role as a researcher did not require them to divulge this level of information as my research aim was to understand the experience of living alone, not of supporting someone who lives alone. It was important, therefore, to acknowledge and be aware of the difference in my roles and the limits to the scope of my research, for the sake of both the informants and the research itself.

3.4. Analysis and Research Findings

In the early stages of analysing my research findings, I became aware of some of my biases beginning to influence the process. When coding interviews with participants with dementia, I began to form a tentative category called 'Denying and Resisting'. I had assumed that participants' comments on coping well and feeling that they were only minimally affected by dementia-related changes were related to denial of dementia and its impact. However, when I compared this to the informants' analysis, I realised I had formed a separate category of 'Coping Well' which included their perception that the person with dementia was managing their difficulties and living alone successfully with dementia. I was surprised and ashamed to find that I had inadvertently dismissed participants' own feelings that they were managing well, and had assumed that because of the dementia, they were unable to recognise they were struggling. However, it seems I am not alone in making this assumption, as other researchers have been quick to assume that positive statements about dementia are due to participants' lack of insight, before further analysis revealed the depth behind such statements (Steeman et al., 2007).

Through this experience, I found a new level of respect for the research process and the constant comparative method of grounded theory (Glaser & Strauss, 1967), without which I may have struggled to move beyond my initial assumption. Triangulation through the use of multiple data sources is a valuable tool in the

research process (Flick, 2004), and this experience has also highlighted to me the importance of gathering information from a range of people in clinical contexts too. For example, gaining multiple perspectives as part of an assessment for dementia could prevent assumptions about the person's level of insight clouding a clinician's judgement without their awareness. I feel I have taken real learning from this process and, in future, I will be more mindful of and open to challenging the assumptions and prejudices that I or my colleagues might bring to either clinical or research situations.

Another element of my research findings that particularly struck me was the wish for many participants to die before their dementia progresses too far. In a sense I did not find it surprising but at the same time it was something I had not fully appreciated before beginning my research. The participants seemed to have varying degrees of commitment to the idea of dying before the later stages of their dementia, with some clearly stating their plans to actively end their lives when they felt it was the right time, and others expressing a faint hope that some other physical illness would take them sooner than the dementia. I found myself torn between feeling sad that they considered death preferable to the future they expected, and happy that they had found some way to maintain control in the face of so much uncertainty.

There has been much media interest in the concept of euthanasia in dementia in recent times, and it has caught my attention in the light of my research findings. Euthanasia (deliberately ending someone's life to prevent suffering) is currently illegal in the UK but has been legal in the Netherlands since 2002 (Kimsma, 2010). It is a controversial topic in relation to dementia; the cognitive deterioration that is characteristic of dementia means that by the time people are ready to end their lives, they will likely have lost the capacity to clearly express that as their wish, yet it is precisely this deterioration that makes euthanasia a potential option in the first place (Hertogh, de Boer, Droes & Eefsting, 2007). Consequently, some people are choosing to die earlier than they would have liked, for fear of being refused at a later stage of their illness (Bomford, 2019).

My personal views on euthanasia are very much mixed, as I can understand the ethical issues on both sides of the debate, particularly in the case of dementia. Before meeting my research participants and hearing their views on the topic, I probably would have leaned more towards being against euthanasia on the whole, most likely due to my own fears about the finality of death. However, my research has given me cause to see the issue from a new perspective, and the experiences and opinions of my participants have affected me profoundly. The question raised in the discussion of the debate on euthanasia in dementia by Hertogh et al. (2007) is a poignant one indeed: "Would we rather lose our life than lose our self?". It seemed to me that this was the question that a number of my participants were asking themselves, and whilst some were definitive in their answer, others were unsure.

Although I now better understand why some people with dementia may wish to end their lives, I am still undecided as to how I would feel in the same situation. In truth, I think nobody can really know how they feel about something as significant as euthanasia without experiencing their own deterioration. I was surprised, however, at how much this aspect of the research findings affected me emotionally and how significant this part was in helping me to understand the experience of living with dementia. I think this new level of understanding will be invaluable in my future encounters with people with dementia and their families. It has also reminded me of the importance of fully immersing myself in my clients' experiences more generally, in order to really appreciate their situation.

3.5. Conclusion

In deepening my understanding of the experience of living alone with dementia I feel I have found a new level of maturity in my understanding of dementia as a whole. I have truly enjoyed my research encounters with people with dementia and their friends and family and have been inspired to consider working clinically with this group in the future. I feel I have learnt a lot about both the client group and

myself as a person and professional, and I have been forced to confront and challenge my own assumptions, biases and beliefs throughout the research process.

I have also very much enjoyed the research itself and have learnt a lot about the value of different research processes such as the constant comparative method. If the opportunity to conduct further research of this nature were to arise in the future, I would be interested to explore in more detail perspectives on dying and dementia; in particular whether opinions differ in people with dementia who live with others. Looking back through my reflective journal has been an enjoyable and enlightening experience, helping me to develop new insights that I might not have noticed at the time. I will certainly make an effort to continue active reflection of this nature in my future clinical and research work.

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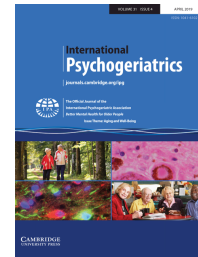
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Appendices

Appendix A: Author instructions for *International Psychogeriatrics*

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.



Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work concerning mental health of older people. It is the official journal of the *International Psychogeriatric Association (IPA)* and is published by Cambridge University Press. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, brief reports, letters to the editor, and invited commentaries and guest editorials. Apart from commentaries and editorials, which are commissioned, contributions to *International Psychogeriatrics* are prepared and submitted by authors. Papers that are not rejected after initial review by the Editor-in-Chief or his representative, are reviewed by at least two expert reviewers selected by the Editor-in Chief. The journal is published twelve times per annum. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. *International Psychogeriatrics* uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission.

The journal does not publish papers whose sole focus is the validation of translated instruments that have previously been well assessed and validated in English or another language. These articles are better placed in a relevant National, rather than an International, journal. (A rare exception may be when social or cultural issues of international significance are clearly involved.) Case reports may be considered for publication only as Letters to the Editor.

Special Note:

Since this is *International Psychogeriatrics*, the authors should seek to highlight international significance of their article in terms of clinical practice, training, or research in different parts of the world. The authors are also advised to go over recent issues of *International Psychogeriatrics* to review papers on related topics, and add how their new submission advances the field further.

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It is not acceptable to submit an article to the journal that has been previously published or is being submitted simultaneously elsewhere. Authors are required to assert that they have not submitted their article elsewhere upon submission to *International Psychogeriatrics*.

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When submitting your manuscript you will need to supply each of the following:

- A cover letter
- The manuscript as a text file in MS Word format (font Arial, minimum size 11)
- Up to 5 suggested reviewers, including their names, institutions, email addresses, and the reason for their appropriateness as reviewers for your article

- All figures in TIFF or JPEG format.

If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading 'Submission of randomized clinical trials' section of these instructions. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:

- That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.
- That the authors have had full control of all the primary data.
- That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers judged to be appropriate for further review will be assessed by two or more reviewers. The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final. The abstract and author details will be seen by prospective reviewers of the manuscript. Authors should suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors' names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers' names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in *International Psychogeriatrics*.

All submissions are acknowledged electronically upon receipt. Most authors can expect to receive an initial decision regarding their paper together with referees' reports within 8 to 10 weeks of submission. Authors who have received no further communication 90 days after acknowledgment of receipt of their article should contact ipaj-ed@cambridge.org.

Article Types

Regular Research Articles: Regular Research Articles are original papers demonstrating the results of scientific studies, based on empirical data. The text of the article should contain no more than 5,000 words, in addition to an abstract of 300 words and up to 60 references. This word count includes only the main body of text (i.e., not abstract, references, tables, or figures).

Brief Reports: This category allows for articles that are shorter than original research but have the same style and may be used to report new and innovative research and/or significant (hot topics). Brief reports are also peer reviewed. They should be of 2,000 words or less and include no more than two figures or tables, no more than 10 references, and have an abstract of no more than 250 words, **without** structured sub-headings.

Reviews of the Literature: Authors intending to submit a literature review should check recent issues of *International Psychogeriatrics* to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles should be of 6,000 words or less, have an abstract of up to 300 words, and may have up to 80 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@cambridge.org). Literature reviews should have an abstract.

Letters to the Editor: Reader's letters will be considered for publication. Letters should be no longer than 750 words, with no more than 1 table or figure, and no more than 10 references. No abstract is required.

Guest Editorials and *Invited Commentaries* are commissioned by the editor.

Organization and style of manuscripts

Title page and corresponding author: Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Each author must select only ONE country as their location. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author's email address, telephone number, fax number and postal address must be clearly stated.

Abstract (Structured): Abstracts for original research and reviews should be structured and incorporate the following headings: Objectives, Design, Setting, Participants, Intervention (if any), Measurements, Results, and Conclusions. Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length. Abstracts for brief reports should not exceed 250 words and should **not** be structured with sub-headings.

Keywords: Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

Running title: This should contain no more than 50 characters including spaces.

Introduction: Briefly state the relevant background to the study to provide the necessary information and context to enable non-specialists to appreciate the objectives and significance of the paper. Most introductions to articles received for review are too long.

Methods: Materials and procedures should be described in sufficient detail to enable replication. Any statistical procedures used should be outlined and their use should be justified here. Results should not be included in the Method(s) section. If statistical procedures are used, they should be described here in adequate detail. Choice of statistical technique should be justified including some indication of the appropriateness of the data for the technique chosen. Adequacy of the sample size for the statistical technique(s) used must be addressed. If appropriate, a description of the statistical power of the study should be provided. If multiple univariate significant tests are used, probability values (p-values) should be adjusted for multiple comparisons, or alternatively a multivariate test should be considered. Significance results (p values) must be presented with accompanying statistics.

Further advice about statistics and *International Psychogeriatrics* can be found in the following article: Chibnall, J. (2000) Some basic issues for clinicians concerning things statistical. *International Psychogeriatrics*, 12, 3-7. The following article may also be of assistance to intending contributors: Chibnall J.T. (2004). Statistical audit of original research articles in *International Psychogeriatrics* for the year 2003. *International Psychogeriatrics* 16, 389-396. Both of these are available at the *International Psychogeriatrics* website by following the above links.

Results: This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation). Wherever possible an indicator of effect size (e.g. Cohens d, η^2 , Cramers V, 95% confidence interval) should be reported in addition to p values. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degrees of freedom (e.g. t, F, χ^2). Terms such as prevalence, population, or control group, should be used appropriately in the scientific sense.

Discussion: Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Results should be interpreted in the light of the size of the effect found and the power of the study to detect differences. Any methodological and other weaknesses of the study should be outlined, including limitations imposed by sample size. Careful consideration of the conclusion(s) for accuracy and alternative interpretation, and possible conflicts or resolution of conflicts in the field is encouraged. Limited speculation and directions for future research can be included.

Conflict of interest declaration: **This section must be completed.** This should follow the discussion and precede the references. Where there is no conflict of interest perceived to be present the heading Conflict of Interest should be included with the single word "none" underneath it. For full details see below.

Description of authors' roles: This section must be completed if the paper has two or more authors. It should contain a very brief description of the contribution of each author to the research. Their roles in formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article should be made plain. For example: H. Crun designed the study, supervised the data collection and wrote the paper. M. Bannister collected the data and assisted with writing the article. N. Seagoon was responsible for the statistical design of the study and for carrying out the statistical analysis.

Acknowledgements: Any acknowledgements other than conflict of interest declarations in regard to sponsorship should be listed briefly here. Acknowledgements imply that the person/s mentioned have approved the citation of their name/s in the paper.

References: For review papers, no more than 75 articles that have been published or are in press should be cited; for regular research articles no more than 60 references, for brief reports no more than 10 references, for commentaries and editorials no more than 10 references, and for letters no more than 10 references. Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript. *International Psychogeriatrics* uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term "et al." should be employed, i.e., (Smith et al., 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith et al., 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.

Reference examples:

For a journal article: **Smith, J., Jones, W. I. and Doe, J. T.** (1996). Psychogeriatrics for pleasure and profit: an expanding field. *International Journal of Unreproducible Results*, 3, 240–242. doi:12.3456/S123456789.

For a book: **Smith, J.A., Brown, P.Q., Jones, H.A. and Robinson, D.V.** (2001). *Acute Confusional States*. New York: Cambridge University Press. For a book chapter. **Park, K., Tiger, B. and Runn, F.** (1999). Psychogeriatrics in context. In G.Verdi and A. Boito, (Eds.) *New Medical Specialties* (pp. 240–260). Cambridge: Cambridge University Press.

Where an article or book chapter has more than six authors only the first author's name should be given followed by the words "**et al.**".

For further examples of reference style see papers in recent issues of *International Psychogeriatrics*.

Figures/Tables: The manuscript should contain no more than five figures or tables (no more than two figures or tables for brief reports). The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the data. The journal has a small budget to permit some color to be printed in come issues but authors wishing to publish figures requiring color to communicate the data may be required to pay some or all the additional cost.

Figure/Table legends: Each caption should begin with a brief description of the conclusion or observation provided in the figure. These should be submitted as a separate section after the References.

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If submitting such supplementary material please follow the instructions below. If referring to supplementary material in a paper the following form of words should be used "see table S1/figure S1/appendix A1 published as supplementary material online attached to the electronic version of this paper at <https://www.cambridge.org/core/journals/international-psychogeriatrics>".

There will normally be one of the following reasons for you to be supplying supplementary material to accompany the online version of your article:

- You wish to link to additional information which due to its nature does not lend itself to print media (examples- full data sets, movie or sounds files etc.)
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N.B. Please note that no copyediting or quality assurance measures will be undertaken on supplementary material (other than to ensure that the file is intact). The authors therefore warrant that the supplementary material that they submit is in a suitable format for publication in this manner. The material shall be published online in exactly the form that it is supplied.

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Please follow these instructions to submit supplementary material:

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- Each supplementary file must have a clear title (for example, Supplementary Figure 1).
- Provide a text summary for each file of no more than 50 words. The summary should describe the contents of the file. Descriptions of individual figures or tables should be provided if these items are submitted as separate files. If a group of figures is submitted together in one file, the description should indicate how many figures are contained within the file and provide a general description of what the figures collectively show.
- The file type and file size in parentheses.
- Ensure that each piece of supplementary material is clearly referred to at least once in the print version of the paper at an appropriate point in the text, and is also listed at the end of the paper before the reference section.

Word limits: The text of Review articles should not exceed 6,000 words, Regular research articles 5,000 words, brief reports 2000 words, and letters to the editor 750 words. The text excludes title page, abstract, acknowledgements, references, tables, and figures. Articles may contain supplementary material which is published online only.

Format and file size: File sizes should be as small as possible in order to ensure that users can download them quickly.

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Authors should limit the number of files to under ten, with a total size not normally exceeding 3 MB. Sound/movie files may be up to 10 MB per file; color PDFs/PowerPoint may be up to 5 MB per file; all other general file types may be up to 2 MB per file but most files should be much smaller.

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In order to ensure the public availability of the results of randomized controlled trials, the International Committee of Medical Journal Editors has suggested that all such trials should be registered. In

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All manuscripts reporting randomized controlled trials should have the following sent with them or they will be returned to the authors.

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- The trial protocol is to be submitted as a supplementary file. This will not be published but it is needed to appraise and peer review the paper. If the protocol is already published, a copy of that paper should be submitted.
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Macromedia Freehand, Adobe Illustrator and Adobe Photoshop are the preferred graphics packages. Before submitting your artwork, please do the following:

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Indicate the file format (e.g. TIFF or EPS), the graphics software that you have used in originating the artwork files (e.g. Freehand 7.0, Illustrator 8.0, etc.) and the computer operating system used (e.g. Mac OS 8.6, Windows NT).

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Pattern fills and tints

Artwork packages do not always generate pattern fills for output on image/platesetters. Imagesetters will interpret them differently from your Mac or PC and the result often looks pixelated or blocked. Where possible, use PostScript fills, custom fills and conventional tints. 9

PostScript fills frequently do not display well on screen but they do print out correctly. It is best to avoid the use of complex or very detailed tints, patterns and symbols. These seldom reproduce satisfactorily when reduced to fit the page and when used in a caption or legend may be completely illegible when represented on a screen (for example during page make-up, or on the Web) or when output on low-quality CUP artwork instructions.doc 2 laser printers. Supplying as TIFF or EPS files (see above) alleviates this problem.

Please therefore:

- Use only the tints, patterns and symbols shown here.
- Use conventional fills: solids, tints, lines or cross-hatching.
- Use a PostScript fill if possible.
- Do not use a screen value above 133 lpi. Generally, 100 lpi is better (even when scanned at high resolution finer tints do not reproduce satisfactorily when reduced).
- If possible, use just one kind of screen (line angle or dot shape) and one screen value throughout the document.
- Do not use pattern fills from a graphics program, as these are usually bitmap patterns, which do not output adequately to plate/image setters.
- Do not use color tints, even if the figure is intended for monochrome printing; use black/white/greyscale.
- Do not use .hairline. line widths in graphics packages.

Monochrome halftone subjects

Figures composed of (hard copy) photographs should be unscreened glossy prints presented at publication scale; each component part should be named with a lower-case letter. Photographic artwork is numbered as part of the sequence of figures, not as separate plates.

If supplying these in digital form, your repro house should follow these instructions:

- Scanning: Scan at a resolution that is around twice the intended screen value; for example scan at 300 dpi for 133 or 150 screen.
- Dot range (halftones only): This is the term we use to describe the highlight/white area and shadow/black areas within a printed image. To prevent the heavy or dark areas of your halftones from filling in or the light areas being washed out we specify a dot range that allows for gains or losses during the process to lithographic printing. Pre-set the dot range at 1% highlight to 96% shadow where possible, we will check your files before outputting as a safeguard.
- Data files: Supply data as TIFF files; if you wish to compress them, use lossless compression software such as the LZW compression package.
- Laser proofs: Supply a good quality laser proof of all figures. List the name and version of the artwork package used and the names and libraries of fonts used in the artwork. If we are unable to use your electronic file, we can scan in the laser proof as an alternative until a revised file can be supplied.
- Line & tone combination: Files scanned as line & tone combination should be scanned at a higher resolution than a standard halftone to ensure better type/line quality, for example, 600 dpi.

Color halftone or line subjects

Do not submit line subject drawings with colored tints unless the figure is required as a color plate; use only black/white/greyscale.

If supplying color subjects in digital form, submit as TIFF or EPS files and choose CMYK color mode when saving your scans. If you supply files as RGB we need to convert them to the CMYK printing process before we can print, this usually results in a slight change of the color values; therefore all color correction must be carried out in CMYK mode on your machine.

General notes

Following acceptance of a manuscript the contact author should receive proofs within 1-12 weeks. They also will be required to complete and forward a copyright form and authors' checklist both of which will be forwarded to the corresponding author by email when the article is accepted.

The average time from an article being accepted to being e-published ahead of print as a First View article is 35 days, provided authors return proofs promptly. E-publication generates a doi number and counts as full publication for citation purposes.

Editorials and commentaries are commissioned by the editor.

Reviewers who reviewed papers in the previous calendar year will be acknowledged in the journal each year. *International Psychogeriatrics* no longer publishes an annual index as modern computerised search techniques have rendered annual hard copy indices obsolete.

Contributors should refer to recent issues of the journal for examples of formatting (abstracts, headings, references, tables, etc.).

Contact Information

Office of the Editor-in-Chief:

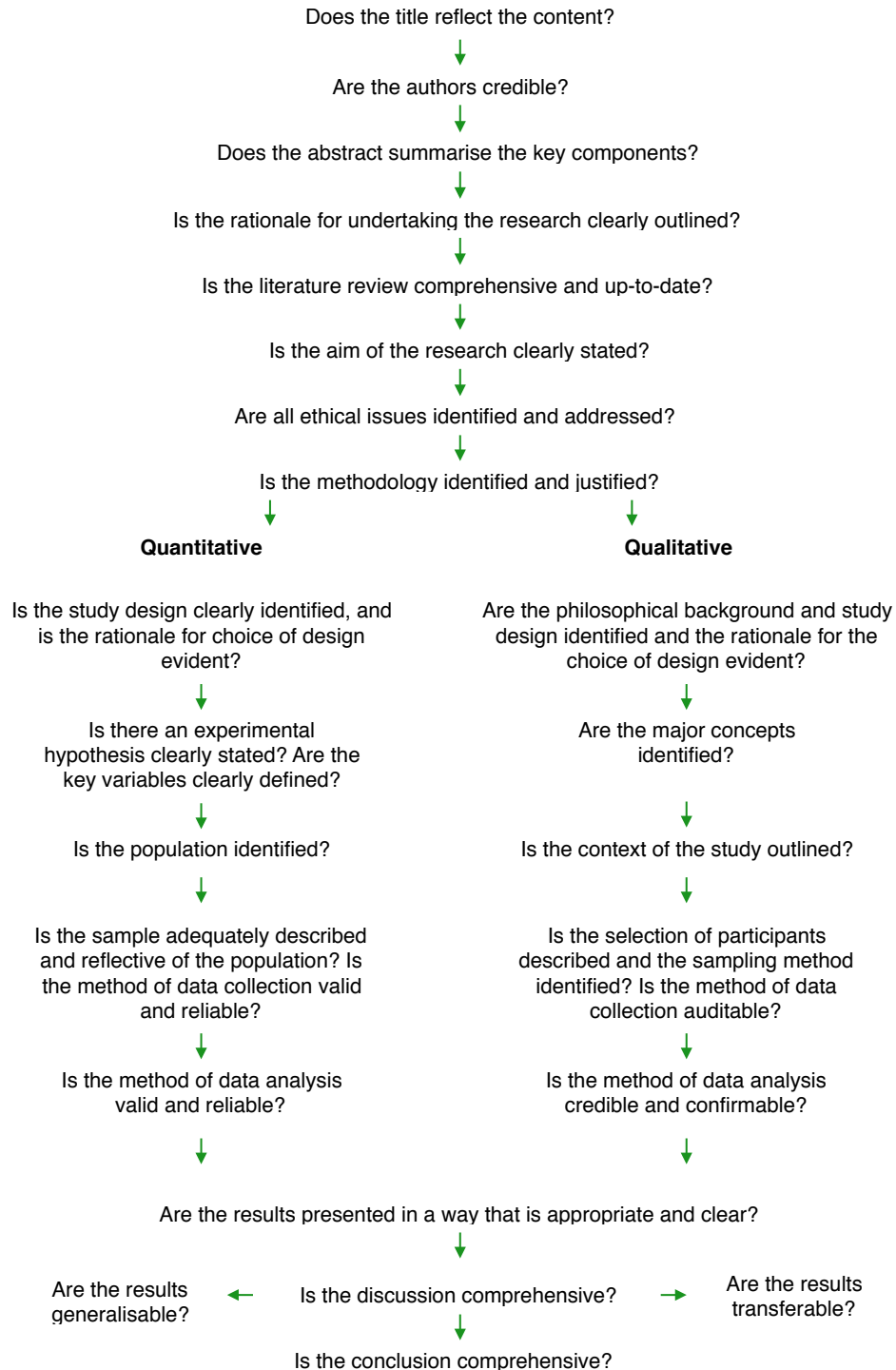
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Web: <http://www.ipa-online.org>

Appendix B: Quality assessment framework



Adapted from Caldwell et al. (2011)

Appendix C: Process for meta-ethnography

From Campbell et al., 2012, p.10

Phase 1: Getting started – ‘identifying an intellectual interest that qualitative research might inform’. This may be changed/modified as interpretive accounts are read.

Phase 2: Describing what is relevant to initial interest – an exhaustive search for relevant accounts can be undertaken followed by selection of research relevant to the topic of interest (they observe that employing all studies of a particular setting often yields trite conclusions).

Phase 3: Reading the studies – the repeated reading and noting of metaphors is required and continues as the synthesis develops.

Phase 4: Determining how the studies are related – the task of putting together the studies requires creating a list of key metaphors, phrases, ideas or concepts (and their relations) used in each account, and juxtaposing them. This leads to initial assumptions about relations between studies.

Phase 5: Translating the studies into one another – the metaphors and/or concepts in each account and their interactions are compared with the metaphors and/or concepts and their interactions in other accounts. These translations are one level of meta-ethnographic synthesis.

Phase 6: Synthesizing translations – ‘the various translations can be compared with one another to determine if there are types of translation or if some metaphors/concepts are able to encompass those of other accounts. In these cases, a second level of synthesis is possible, analysing types of competing interpretation and translating them into each other’ to produce a new interpretation/conceptual development.

Phase 7: Expressing the synthesis – for the proposed synthesis to be communicated effectively it needs to be expressed in a medium that takes account of the intended audience’s own culture and so uses concepts and language they can understand.

Appendix D: Author instructions for *Dementia*

Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/dementia> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of *Dementia* will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.



1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to *Dementia*, please ensure you have read the [Aims & Scope](#).

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 2,500-3,000 words. Innovative practice papers should include the words 'Innovative Practice' after the title of their article when submitting to the journal. For further information about innovative practice papers, please refer to the [guidelines](#).

The journal also publishes book reviews.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on [how to get published](#), plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the [Funding Acknowledgements](#) page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations [here](#).

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the [World Medical Association Declaration of Helsinki](#).

Submitted manuscripts should conform to the [ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals](#), and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the [ICMJE Recommendations for the Protection of Research Participants](#).

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' [International Standards for Authors](#) and view the Publication Ethics page on the [SAGE Author Gateway](#).

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the [SAGE Author Gateway](#) or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the [SAGE Author Gateway](#).

3.3 Open access and author archiving

Dementia offers optional open access publishing via the SAGE Choice programme. For more information please visit the [SAGE Choice website](#). For information on funding body compliance, and depositing your article in repositories, please visit [SAGE Publishing Policies](#) on our Journal Author Gateway.

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the [Manuscript Submission Guidelines](#) page of our Author Gateway.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'. We recommend that authors refer to the [Dementia Engagement and Empowerment Project \(DEEP\) guidance](#) which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information. Alternatively, Alzheimer's Australia sets out [guidelines for dementia-friendly language](#). Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the

submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our [guidelines on submitting supplementary files](#).

4.4 Reference style

Dementia adheres to the APA reference style. View the [APA](#) guidelines to ensure your manuscript conforms to this reference style.

4.5 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.

[Back to top](#)

5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty [REDACTED].

Books for review should be sent to: Book Review Editor, Dementia, Caroline Swarbrick University of Manchester, UK [REDACTED]

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of [ORCID](#), the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities ensuring that their work is recognised.

We encourage all authors to add their ORCIDs to their SAGE Track accounts and include their ORCIDs as part of the submission process. If you don't already have one you can create one [here](#).

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a separate file.

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the [SAGE Author Gateway](#).

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the [SAGE Journals help page](#) for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the [Promote Your Article](#) page on the Gateway for tips and advice. In addition, SAGE is partnered with Kudos, a free service that allows authors to explain, enrich, share, and measure the impact of their article. Find out how to [maximise your article's impact with Kudos](#)

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Appendix E: Participant invitation emails for volunteers on the online database

Representative

Dear y,

I am contacting you as the representative of x on the Join Dementia Research database.

X has matched to my study, Living Alone with Dementia and I am contacting you to see whether s/he might be interested in taking part.

The study aims to learn about the experience of living alone with dementia, in order to better inform services that support this group of people. It will involve a face-to-face interview lasting around 1 hour. The interview time and location will be arranged to suit the participant.

I am looking specifically for people who have a diagnosis of dementia and who live on their own. Participants will need to be able to take part in a verbal interview and to give their own consent to take part.

Participants will also be asked to nominate a friend or family member who knows them well to be interviewed about them. It may be that as x's representative on [database], you will be the nominated person. This will be a separate interview at a time and place to suit you.

More information about my study can be found when you log in on Join Dementia Research [link] and I have attached my participant information sheet to this email.

Please let me know whether or not x would be interested in taking part in this study.

I look forward to hearing from you.

Best wishes,

Courtney Poole

Representative + Individual

Dear x and y

I am contacting you as x has matched to my study, Living Alone with Dementia, on the Join Dementia Research database. X, I am wondering whether you might be interested in taking part.

The study aims to learn about the experience of living alone with dementia, in order to better inform services that support this group of people. It will involve a face-to-face interview lasting around 1 hour. The interview time and location will be arranged to suit the participant.

I am looking specifically for people who have a diagnosis of dementia and who live on their own. Participants will need to be able to take part in a verbal interview and to give their own consent to take part.

Participants will also be asked to nominate a friend or family member who knows them well to be interviewed about them. It may be that as x's representative on [database], you, y, will be the nominated person. This will be a separate interview at a time and place to suit you.

More information about my study can be found when you log in on Join Dementia Research [[link](#)] and I have attached my participant information sheet to this email.

X, please let me know whether or not you would be interested in taking part in this study.

I look forward to hearing from you.

Best wishes,

Courtney Poole

Individual

Dear x

I am contacting you as you have matched to my study, Living Alone with Dementia, on the Join Dementia Research database. I am wondering whether you might be interested in taking part.

The study aims to learn about the experience of living alone with dementia, in order to better inform services that support this group of people. It will involve a face-to-face interview lasting around 1 hour. The interview time and location will be arranged to suit you.

I am looking specifically for people who have a diagnosis of dementia and who live on their own. Participants will need to be able to take part in a verbal interview and to give their own consent to take part.

Participants will also be asked to nominate a friend or family member who knows them well to be interviewed about them. This will be a separate interview at a time and place to suit them.

More information about my study can be found when you log in on Join Dementia Research [[link](#)] and I have attached my participant information sheet to this email.

X, please let me know whether or not you would be interested in taking part in this study.

I look forward to hearing from you.

Best wishes,

Courtney Poole

Appendix F: Interview guide

What are the good and bad things about living on your own?

(What do you think are the good and bad aspects of living alone for [name]?)

- Positive aspects of living alone
- Difficulties or concerns with living alone

How does having dementia affect you on a day-to-day basis?

(How do you feel dementia affects [name] on a day to day basis?)

- Ways in which cognitive impairments affect day-to-day life
- Coping strategies

Could you tell me about other people that you see or talk to?

(Could you tell me about other people that [name] sees or talks to?)

- Contact with other people
- Involvement or support of others
- Relationships/roles (and any continuity or change in these)

Overall, how do you feel about your life?

(Overall, how do you feel about their situation?)

- View of current situation
- Perspective on the future (including any plans)

Is there anything else you'd like to add?

Additional/general prompts (if required):

- Can you tell me a bit more about that?
- Can you think of an example of that?
- I'd like to bring you back to what you were saying about...can you say a bit more about that again?

Appendix G: Ethical approval - Coventry University



Certificate of Ethical Approval

Applicant:

Courtney Poole

Project Title:

Living alone with dementia

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

Date of approval:

23 April 2018

Project Reference Number:

P62964

**REGISTRY RESEARCH UNIT
ETHICS REVIEW FEEDBACK FORM**

(Review feedback should be completed within 10 working days)

Name of applicant: Courtney Poole.....

Faculty/School/Department: [Faculty of Health and Life Sciences] School of Psychological, Social and Behavioural Sciences

Research project title: Living alone with dementia

Comments by the reviewer

1. Evaluation of the ethics of the proposal:	
Clear, detailed protocol.	
2. Evaluation of the participant information sheet and consent form:	
The participant information sheet and consent form are clear.	
3. Recommendation: (Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to re-submit his/her application and this will be sent to the same reviewer).	
<input checked="checked" type="checkbox"/>	Approved - no conditions attached
<input type="checkbox"/>	Approved with minor conditions (no need to re-submit)
<input type="checkbox"/>	Conditional upon the following – please use additional sheets if necessary (please re-submit application)
<input type="checkbox"/>	Rejected for the following reason(s) – please use other side if necessary
<input type="checkbox"/>	Not required

Name of reviewer: Anonymous

Date: 04/04/2018.....

Appendix H: Ethical approval – IRAS (NHS)



Miss Courtney Poole
Clinical Psychology Doctorate, Faculty of Health and Life
Sciences
James Starley Building, Coventry University
Priory Street, Coventry
CV1 5FB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

13 July 2018

Dear Miss Poole

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Living alone with dementia
IRAS project ID:	238910
Protocol number:	P62964
REC reference:	18/EM/0150
Sponsor	Coventry University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?

You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the “*summary of assessment*” section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a ‘green light’ email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

Page 1 of 7

IRAS project ID	238910
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How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Mr Tom Patterson

Tel: [REDACTED]

Email: [REDACTED]

IRAS project ID	238910
-----------------	--------

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **238910**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

*Copy to: Professor Olivier Sparagano, R&D Contact, Coventry University
Ms Joanna Sampson, Sponsor Contact, Worcestershire Health and Care NHS
Trust*

IRAS project ID	238910
-----------------	--------

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Ethical Approval Certificate (Coventry University)]	1	23 April 2018
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Ethical Review Comments (Coventry University)]	1	23 April 2018
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Ethical Review (Coventry University)]	1	23 April 2018
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Ethical Approval Document (Coventry University)]	1	23 April 2018
Covering letter on headed paper [REC response covering letter]		29 June 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance]	1	23 April 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance]	1	30 April 2018
HRA Schedule of Events	1.0	21 June 2018
HRA Statement of Activities	1.0	21 June 2018
Interview schedules or topic guides for participants [Interview Protocol (Person with dementia)]	2	14 June 2018
Interview schedules or topic guides for participants [Interview Protocol (Informant)]	2	14 June 2018
IRAS Application Form [IRAS_Form_11052018]		11 May 2018
Letter from sponsor [Sponsor Letter]	1	23 April 2018
Other [Liability Insurance]	1	23 April 2018
Other [Pre-validation e-mail]		11 May 2018
Other [E-mail re the process for passing contact details to the researcher]		18 May 2018
Participant consent form [Consent for contact details]	1	10 May 2018
Participant consent form [Participant Consent Form]	4	11 June 2018
Participant consent form [Informed consent form (Informant)]	1	11 June 2018
Participant information sheet (PIS) [Participant Information Sheet]	5	11 June 2018
Participant information sheet (PIS) [Participant Information Sheet (Informant)]	1	11 June 2018
Participant information sheet (PIS) [Participant Debrief Sheet]	3	14 June 2018
Research protocol or project proposal [Research Protocol]	4	14 June 2018
Summary CV for Chief Investigator (CI) [Curriculum Vitae (Chief Investigator)]	1	30 April 2018
Summary CV for supervisor (student research) [Curriculum Vitae (Supervisor)]	1	30 April 2018

IRAS project ID	238910
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Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	<p>The sponsor has submitted the HRA Statement of Activities and intends for this to form the agreement between the sponsor and study sites.</p> <p>The sponsor is not requesting, and does not require any additional contracts with study sites.</p>
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. No study funding will be provided to sites, as detailed at Schedule 1 of the Statement of Activities.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments

IRAS project ID	238910
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Section	Assessment Criteria	Compliant with Standards	Comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Local Collaborator should be appointed at study sites.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

IRAS project ID	238910
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HR Good Practice Resource Pack Expectations

<i>This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken</i>
Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in A18 of the IRAS form, would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

<i>This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.</i>
The applicant has indicated that they <u>do not intend</u> to apply for inclusion on the NIHR CRN Portfolio.

Appendix I: Consent form (person with dementia)

IRAS Project ID: 238910



Living Alone with Dementia

Informed Consent Form



This research project aims to learn about the experiences of people who live on their own with a diagnosis of dementia. You have been invited to take part because you live on your own and have a diagnosis of dementia.

You will be interviewed about your experiences of living alone with dementia. The interview will be voice recorded so that it can be transcribed at a later date.

Please tick

1. I have read and understood the participant information sheet (dated 11/06/18, version 5) and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.

☐

3. I understand that the information I provide will be treated as confidential, unless I disclose that I or someone else is at risk of harm.

☐

4. I understand that I have the right to withdraw my data at any point after my interview.

☐

5. I agree to the interview being audio recorded.

☐

6. I agree to quotations from my interview being used in the report. Quotes will use a pseudonym and it will not be possible to identify who said them.

☐

7. I agree to take part in the research project.

☐

8. I give permission for the person named below to be approached and interviewed as part of the research project.

☐

Name of informant.....

9. I would like to receive a brief summary of the results upon completion of the project in July 2019, and give permission for the researcher to keep my contact details for this purpose.

☐

Name of participant:

Signature of participant:

Date:

Name of Researcher:

Signature of researcher:

Date:

V4 11/06/2018

Appendix J: Consent form (informant)

IRAS Project ID: 238910



Living Alone with Dementia Informed Consent Form (Informant)



This research project aims to learn about the experiences of people who live on their own with a diagnosis of dementia. You have been nominated by someone who lives on their own with a diagnosis of dementia who has taken part in the study.

You will be interviewed about your views on living alone with dementia and your experience of the person who has nominated you. The interview will be voice recorded so that it can be transcribed at a later date.

1. I have read and understood the participant information sheet for informants (dated 11/06/18, version 1) and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.
3. I understand that the information I provide will be treated as confidential, unless I disclose that I or someone else is at risk of harm.
4. I understand that I have the right to withdraw my data at any point after my interview.
5. I agree to the interview being audio recorded.
6. I agree to quotations from my interview being used in the report. Quotes will use a pseudonym and it will not be possible to identify who said them.
7. I agree to take part in the research project.
8. I would like to receive a brief summary of the results upon completion of the project in July 2019.

Please tick

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

Name of participant:

Signature of participant:

Date:

Name of Researcher:

Signature of researcher:

Date:

V1 11/06/2018

Appendix K: Participant information sheet (person with dementia)



Living Alone with Dementia **Participant Information Sheet**



You are being invited to take part in a research project; Living Alone with Dementia. This document provides more information about the project to help you decide whether you would like to take part. You will also have the opportunity to ask the researcher any other questions that you may have.

Information about the project

This research project aims to learn about the experiences of people who live on their own with a diagnosis of dementia. It is being completed for educational purposes as part of the lead researcher's Doctorate in Clinical Psychology qualification.

Why have I been chosen?

You have been invited to take part in the study because you live on your own and have a diagnosis of dementia. Your support group leader or NHS professional has suggested that you may be interested in taking part in this research. Alternatively, you may have registered to take part in research through the Join Dementia Research database.

Do I have to take part?

No. It is up to you whether you choose to take part in the research or not. Your NHS care or support group participation will not be affected in any way if you choose not to take part.

What do I have to do?

If you choose to take part, you will be invited to be interviewed about your experiences of living alone with dementia. The interview will be voice recorded. The time and place of the interview will be agreed to suit you. The interview will last about 1 hour. The lead researcher, Courtney Poole, will conduct the interview. She will also transcribe (type up) the interview.

You will also be asked to nominate a friend or family member who knows you well. You will be asked to give your permission for this person to be interviewed about their views on living alone with dementia and their experience of knowing you. This study aims to understand the views of different people who live alone with dementia. We are also interested in the views of people who know or support someone living alone with

dementia, and they will be asked to talk about your contact and interactions with others. These different views and perspectives will help us to develop a theory (explanation) of the experience of living alone with dementia.

What are the risks associated with this project?

There is a small chance that you may become upset during the interview, though every effort will be made to help you feel comfortable. You will be able to end the interview at any time. Should you become distressed during the interview, you will also be asked if you would like your friend or family member to be told, and they will be contacted if you wish. You will be given written information about some sources of support after the interview.

What are the benefits of taking part?

There will be no direct benefit to you for taking part in the study. However, by taking part you will be contributing to a better understanding of the needs and experiences of people with dementia who live alone.

Withdrawal options

You can choose to withdraw at any point before the interview and can end the interview at any time. You can also withdraw your data at any point after your interview by contacting the lead researcher Courtney Poole using the contact details below. You do not have to give a reason for withdrawing and there will be no impact on your NHS care or support group participation.

Data protection & confidentiality

The audio recording of your interview will be deleted as soon as the interview has been typed up. Written records will be kept in a password protected document and will not contain your name or personal information. Your consent form will be kept in a locked cabinet separate from the interview data and destroyed at the end of the study.

Your contact details will be stored securely in a password-protected document on an encrypted memory stick. They will be deleted upon completion of your interview, or after you have been sent the study results summary if you have indicated that you would like to receive this. The contents of the interview will be confidential and it will not be possible for you to be identified from it. However, if you suggest that you or someone else is at risk of harm, the researcher may have to share this information with others in order to keep you safe. This will be discussed with you where possible at the time of the interview.

What will you do with my information?

Coventry University is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Coventry University will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Professor Olivier Sparagano using the details at the bottom of this leaflet.

What will happen with the results of the study?

The results will be submitted as part of a thesis for a Doctorate in Clinical Psychology. The study may be presented at conferences and published in peer-reviewed journals. It will not be possible to identify you in the written report of this study. Any quotations will use a pseudonym.

You will be asked at the time of your interview whether you would like to receive a short summary of the research findings. This will then be sent to you upon completion of the study in July 2018.

Who has reviewed this study?

The study has received ethical approval from Coventry University Ethics and from the NHS ethics body, IRAS. The study was approved by the Leicester South Research Ethics Committee, which is part of the Health Research Authority.

What if I have a complaint?

If you have any concerns about the research and/or would like to make a complaint please contact either the research supervisor Tom Patterson or the Associate Pro-Vice Chancellor for Research Professor Olivier Sparagano using the details below.

You can also complain to a Patient Advice and Liaison Service (PALS). Please see below for details.

Further information/Key contact details

Lead researcher – Courtney Poole: [REDACTED]

Research supervisor (Coventry University) – Tom Patterson:
[REDACTED]

Associate Pro-Vice Chancellor for Research (Coventry University) –
Professor Olivier Sparagano: [REDACTED]
[REDACTED]

Patient Advice and Liaison Service

Worcester Health and Care Trust: WHCNHS.PALS@nhs.net, 01905 681517

If Worcester is not your local Trust, please contact NHS England:
England.contactus@nhs.net, 0300 311 22 33

Appendix L: Participant information sheet (informant)



Living Alone with Dementia **Participant Information Sheet** **(Informant)**



You are being invited to take part in a research project; Living Alone with Dementia. This document provides more information about the project to help you decide whether you would like to take part. You will also have the opportunity to ask the researcher any other questions that you might have.

Information about the project

This research project aims to learn about the experiences of people who live on their own with a diagnosis of dementia. It is being completed for educational purposes as part of the lead researcher's Doctorate in Clinical Psychology qualification.

Why have I been chosen?

You have been nominated by someone you know who lives alone with dementia. This person has taken part in the research and has identified you as someone who knows them well. They have given their consent for you to be interviewed about them.

Do I have to take part?

No. It is up to you whether you choose to take part in the research or not. The person who nominated you will still be able to remain in the study, even if you decide not to take part.

What do I have to do?

If you choose to take part, you will be invited to be interviewed about your views on living alone with dementia and your experience of knowing the person who nominated you. The interview will be voice recorded. The time and place of the interview will be agreed to suit you. The interview will last about 1 hour. The lead researcher, Courtney Poole, will conduct and transcribe (type up) the interview.

What are the risks associated with this project?

There is a small chance that you may become upset during the interview, though every effort will be made to help you feel comfortable. You will be able to end the interview at any time. Should you become distressed during the interview, you will also be asked if you would like a friend or family

member to be told, and they will be contacted if you wish. You will be given written information about some sources of support after the interview.

What are the benefits of taking part?

There will be no direct benefit to you for taking part in the study. However, by taking part you will be contributing to a better understanding of the needs and experiences of people with dementia who live alone.

Withdrawal options

You can choose to withdraw at any point before the interview and can end the interview at any time. You can also withdraw your data at any point after your interview by contacting the lead researcher Courtney Poole using the contact details below. You do not have to give a reason for withdrawing and there will be no impact on your friend or family member's participation in the study.

Data protection & confidentiality

The audio recording of your interview will be deleted as soon as the interview has been typed up. Written records will be kept in a password protected document and will not contain your name or personal information. Your consent form will be kept in a locked cabinet separate from the interview data and destroyed at the end of the study.

Your contact details will be stored securely in a password-protected document on an encrypted memory stick. They will be deleted upon completion of your interview, or after you have been sent the study results summary if you have indicated that you would like to receive this.

The contents of the interview will be confidential and it will not be possible for you to be identified from it. However, if you suggest that you or someone else is at risk of harm, the researcher may have to share this with others in order to keep you safe. This will be discussed with you where possible at the time of the interview.

What will you do with my information?

Coventry University is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Coventry University will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Professor Olivier Sparagano using the details at the bottom of this leaflet.

What if I have a complaint?

If you have any concerns about the research and/or would like to make a complaint please contact either the research supervisor Tom Patterson or the Associate Pro-Vice Chancellor for Research Professor Olivier Sparagano using the details at the bottom of this leaflet.

What will happen with the results of the study?

The results will be submitted as part of a thesis for a Doctorate in Clinical Psychology. The study may be presented at conferences and published in peer-reviewed journals. It will not be possible to identify you from the written report. Any quotations will use a pseudonym.

You will be asked at the time of your interview whether you would like to receive a short summary of the research findings. This will then be sent to you upon completion of the study in July 2018.

Who has reviewed this study?

The study has received ethical approval from Coventry University Ethics and from the NHS ethics body, IRAS. The study was approved by the Leicester South Research Ethics Committee, which is part of the Health Research Authority.

Further information/Key contact details of researcher and supervisor

Lead researcher – Courtney Poole:



Research supervisor (Coventry University) – Tom Patterson:



Associate Pro-Vice Chancellor for Research (Coventry University) –
Professor Olivier Sparagano: [REDACTED]

[REDACTED]

Appendix M: Debrief sheet



Living Alone with Dementia Participant Debrief Sheet



Thank you for taking part in the research project "Living Alone with Dementia".

It is possible that the interview has brought up a range of feelings for you. You may also have questions or concerns that have come up from the interview. The researcher will discuss these with you now.

Following this, if you feel you need any healthcare support, the researcher will advise you to contact the person who referred you to the study; (your NHS clinician or support group leader) in the first instance. If you feel you need any further support, the details of some relevant support services are listed here:

- Alzheimer's Society: <https://www.alzheimers.org.uk> 0300 222 11 22
- Age UK: <https://www.ageuk.org.uk> 0800 055 6112
- Dementia UK: <https://www.dementiauk.org> 0800 888 6678
- Carer's Trust: <https://carers.org>

Withdrawing from the Research

If you have changed your mind about taking part in this research, you are welcome to withdraw your data at any time and without giving a reason. Please contact the lead researcher Courtney Poole using the details below.

Research Team Contact Details

- Lead researcher – Courtney Poole: [REDACTED]
- Research supervisor (Coventry University) – Tom Patterson: [REDACTED]
- Associate Pro-Vice Chancellor for Research (Coventry University) – Professor Olivier Sparagano: [REDACTED]

Appendix N: Initial coding – example transcript excerpt

48 without sleeping. So I don't think that helps me to be honest but there you go, I
 49 can't...there's nothing I can do about that. I've tried all homeopathic remedies and all of
 50 that but there's nothing...but I've been like it since I was a child anyway. *Lack of sleep
impacting on
dementia's
symptoms*

51 P: But so...so yeah that's the sort of thing that's happening. So I'll go and lie down and once I
 52 wake up, I'll get up and just carry on as normal. You know, if I'm stuck for anything I'll phone
 53 my daughter-in-law or my niece up, you know and say ah how do you do this cuz I've
 54 forgotten a little bit...but other than that, I'm okay. Living with it. *asking for
help when
confused -
ringing niece
or daughter in
law*

55 R: Yeah. And you mentioned you've lived on your own since...
 56 P: Since March, yeah. Since my husband died. Yeah.
 57 R: How have you been finding it on your own?
 58 P: Okay yeah. I manage. I manage to cook and clean and still do all do the things I used to
 59 do. As I said, the only thing that gets me is if I can't remember something. Like the other
 60 day...or I'll say the other week it was, I got...and I do it every morning, I have two boiled eggs
 61 for my breakfast, almost every morning. I have cereal some of the time but most of the time
 62 I have boiled eggs. And...I had the pan in my hand, and I put two eggs in it and the water...no
 63 sorry I didn't put the water in, I put two eggs in it. And I thought...what do I do now? It had
 64 gone. And I nearly actually phoned my daughter-in-law up, I just couldn't work it out. I
 65 thought what do I do? I do this all the time, what do I do, what do I do? And I thought right
 66 okay put it down [P]...and I put it down. And I made myself a coffee and I came and sat
 67 down. And I had my coffee and...it came back to me. Oh yes you haven't had your breakfast,
 68 go and do your eggs. And I could see I'd put them in a pan but I'd put no water. So I put the
 69 water in and I put them on. And what I do when I do my boiled eggs, which you're probably
 70 not interested in but I put a mug of water in the microwave for three minutes exactly. And
 71 once my eggs start to boil, cuz I do them from cold, once they start to boil I take them out
 72 and they're just right, soft. So that's how to do boiled eggs. *managing day to
day tasks day
forgetting how
to do day to
day things
(boil eggs)*

73 R: Right, thank you!
 74 P: So yeah things like that happen to me quite often.
 75 R: So you find that taking a break helps...
 76 P: I take a break and I do something different. And that to me...helps me, it might not help
 77 anybody else but it helps me. *taking a
break / doing
something
different*

78 R: Just to sort of reset.
 79 P: Yes. It is resetting really, resetting my brain...my mind to what I've got to do. And I can get
 80 up and...I do the normal things like go into a room and think what the heck did I come in
 81 here for. And I have to come back out...but I was doing that for years anyway. But now it's...I
 82 can't...I can't sometimes...remember what...how can I explain it...I can't remember what I've
 83 gone in for...but I also...when I come and sit down and I...then I reset myself, when I do
 84 remember I think well what was I going to get that for. Do you know what I mean, so it's
 85 that kind of thing that's going on with me. And it's still going on with me. What was I going
 86 to get it for anyway? *finding what
helps me*

87 R: So that's a bit different to the kind of forgetting you noticed before.
 88 P: Yeah. You know, when you go into a room...normally when you go back into the room
 89 where you first thought of it, you'll remember. And that does happen sometimes. But
 90 what's happening now is that I don't know what I wanted it for anyway. So that other
 91 thought process has gone. *resetting my
brain*

92 P: And also what happens...I have a list, everything has to be written. Everything has to be
 93 written. And...if...if I'm in the kitchen and I'll say oh I'm running out of bread, right I want
 94 bread. Okay. And if I fail to come in and write it down straight away...I might remember
 95 *noticing a
different type
of forgetfulness
since dementia*

*losing thought
processes*

*writing every-
thing down
straight away*

95 that, but if I find something else I want...milk...the bread's gone. So as far as I know I want
 96 milk. So I'll come and write milk down. And I'll go to the shops and I'll come back...got no
 97 bread. Do you know what I'm saying, so those type of things happen to me quite a lot.
 98 [Laughing] Quite a lot. Unless I write it straight down. If I write it straight down I'm okay. But
 99 if I don't write it down...

100 R: So that's a way that you've found to manage that, to write it straight down.
 101 P: Yeah that's...my diary, see it's full of all kinds of things I have to write down. And I have a
 102 pad here that I have to write stuff down that I need. You know, when I make a Tescos list or
 103 whatever.
 104 R: Are there any other kind of tricks that you've found that help you to manage some of the
 105 difficulties?
 106 P: Umm...no not really I can't think of anything.

107 R: So taking a break and writing things down are the two main things.
 108 P: Taking a break...and thinking about something else. And seeing to that something else.
 109 And then going back to...what it was I couldn't remember or couldn't recall doing. And then
 110 trying to analyse it, you know and trying...I've always been that way of trying to work out
 111 things for myself rather than depend on other people. I've always had to work hard, you
 112 know to bring my children up, I've always had to work hard and...well you know you work at
 113 it and...you know. But I've always done it. I've always done that. And I've thought about
 114 things before I've done them...to make sure I don't do anything that's not right for other
 115 people. I'd hate to do anything bad to anybody. Or if there's bad feeling...come and tell me
 116 what I've done because I would be so upset if I thought I'd hurt somebody.
 117 R: So you're quite a thoughtful analytic type of person.
 118 P: I am yeah, I am.

119 R: And it sounds like that's helping you to manage some of the difficulties.
 120 P: Yeah. And I do a lot of um...puzzles. I do crosswords, sudoku and I read. I watch
 121 television...I try to keep my brain as active as I can. So you know...I think it helps. The doctor
 122 came and gave us a talk, said all that will do is make you better at puzzles. And I said right
 123 okay, I didn't agree with him. But there you go, not everybody thinks the same do they.
 124 R: What for you are the good things about living here on your own?
 125 P: Independence. Mostly. That's the first thing. I can be independent...if I lived at my son's,
 126 with my son and daughter in law. But um...while...it's still to an extent, I'd still be sharing
 127 their lounge. I could come and go as I pleased...but if a football match was on and he
 128 wanted to watch it...he could and I can't watch the programme I want to watch...and...I
 129 can...[daughter in law] would insist on doing all the cooking. And I like to cook, I like to bake.
 130 She'd let me have a day where I would do it but it's not the same as your own home. You
 131 know, this is my home and I like it here. I like to be able to, you know, get up when I want...I
 132 like to be able to...I know this is going to sound crude, I like to be able to break wind if I need
 133 to [laugh] and if I fancy a sandwich I won't feel as if I'm being greedy, you know if I haven't
 134 long since had breakfast or something if I was at my son's or that sort of thing. I go twice a
 135 week for dinner. And they come down, make sure I'm okay. But they've got their business.
 136 They've got their business and I don't like to put on them anyway. I prefer my
 137 independence, I can have my own things around me...you know.
 138 R: You've got your own stuff, you can do what you want.
 139 P: It's all my own, yeah. If I don't feel like dusting that day I don't, you know. So...if I went
 140 and lived there I would feel obliged to do things [laughing] and I wouldn't want to do them
 141 sometimes.

writing
reminders to
self

analysing
what I'm doing

working things
out myself -
not wanting
to rely on others

always having
thought through
my decisions
not wanting to
upset anyone

doing puzzles and
crosswords
reading, watchi
- keeping my
brain active

being independent

being able to do
what I want
when I want

not having to
be polite for
others
(parting when
I want!)

not being
judged for what
I'm doing

seeing family
regularly

not wanting
to burden
them

having my own
things around
me

not feeling obliged
to do things

142 R: Yeah. Do you have any concerns about being on your own? OR anything that's more
 143 difficult?
 144 P: No, I really don't. As I said, if I do feel...mm I shouldn't say...really...I shouldn't say no to
 145 that really. Because I suppose I do...because there might come a time...where I won't...I'll
 146 forget to put the cooker off or something and I'd hate for me to get to that stage. You know
 147 and make it dangerous for myself, I don't want to do that. So I suppose I've got to say yes to
 148 that, there would come a time. But I think that...I would...not...sorry I've lost the frame. I've
 149 lost the frame of thinking.
 150 R: That's alright. You were talking about possibly putting yourself in dangerous situations at
 151 some point in the future, and that's a bit of a worry.
 152 P: Yeah, at some point...if it comes to that then I would recognise that. And say oh heck, this
 153 doesn't need to happen again. And if it does then I will get in touch with my son I think...and
 154 say I'm going to have to move in. Because um...they would be willing to have me there.
 155 R: And is that something you would feel comfortable with at that kind of stage?
 156 P: I would...in one way and I wouldn't in another. I would in the way that you know, I know
 157 they're on hand. But in another way...I'd be frightened to go and make a cup of tea if I got to
 158 that stage, in case I...you know...have I put the water in the kettle or...do you know what I
 159 mean, if I got to that stage, and I'm not at that stage yet...but I'm not silly, I know that it
 160 might come...but I'm certainly not there yet. I'm still...quite compos mentis. You know.
 161 R: Do you have any ideas in mind about how you might manage some of those difficulties, if
 162 and when they come?
 163 P: Um...no not really. No I...I don't want to face that yet.
 164 R: You're kind of a day-by-day person.
 165 P: Yeah. I do plan things...in...you know in futures but um...all that gets written in my diary,
 166 my plan...things I plan to do. But um...no.
 167 R: Is that something that you think helps you to manage, to kind of take things day by day?
 168 P: I think so. Because I force myself to...to know what I'm doing. Every action I do, I tell
 169 myself what I'm doing. You know...and, say if I went to lift that I'd say you know lift your
 170 iPad [P], have a look see if you've got any messages or anything, you know. And I...I think
 171 that I don't...sometimes I say it out loud. So every action I do, I think about before I do it. So
 172 that it all makes sense. If it doesn't make sense...cuz I get my odd days when things don't
 173 make sense. And I'll say no that's not right [P], that doesn't make sense, go and lie down.
 174 And I'll go into my bedroom and I'll lie down. And inevitably fall asleep.
 175 R: So you're able to recognise when something's not quite right
 176 P: Yeah I am at this point of the dementia, yeah I am.
 177 R: And that helps you to do something different.
 178 P: Yeah. It does, yeah it does.
 179 [pause in interview while P moved position]
 180 R: So you've mentioned about your memory and how you write things down to manage, are
 181 there any other ways in which dementia affects you day to day?
 182 P: No not really, I don't think so. No, other than what I've mentioned.
 183 R: Those are the main difficult things?
 184 P: Those are the main things, yeah.
 185 R: You've told me about ways that you've found to manage those, so taking a break, doing
 186 something different. And that kind of self-commentary.
 187 P: That's right yeah, all that helps. It does help. But you know, that's...that's something
 188 [husband] used to say to me, you know...tell yourself what you're doing. Analyse it in your

not having
anyone about
being alone
worrying about
future dementia
becoming
dangerous to
self
losing train
of thought
planning for
the future -
looking out
for signs I'm
worse
knowing
someone's
around
being frightened
of what might
do
still being aware
and competent
Not wanting to
think about
future difficulties
taking things
day by day (as
they come)
commentating
on what I'm
doing to check
it makes sense
having odd days
when things don't
make sense
being able to
recognise when
I'm not right
at this stage
of dementia
taking advice
from others